EXAMINING HOW TO STRENGTHEN THE PRIMARY HEALTH CARE CAPACITY FOR EARLY BREAST CANCER DETECTION IN UGANDA: A SOCIOECOLOGICAL APPROACH

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COPYRIGHT STATEMENT

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ABSTRACT

Breast cancer in Uganda is usually detected late as a result of complex and interacting factors. Although primary health care (PHC) is an integral platform for facilitating early detection of breast cancer in low-income countries (LICs), this has not been fully explored in Uganda. Thus, this study critically examined how the PHC capacity can be strengthened to deliver early breast cancer detection services for women in Kajjansi town council, a semi-rural community in Uganda.

This study was conducted through a sequential explanatory mixed methodology design using quantitative and qualitative approaches. The quantitative phase evaluated the existing PHC capacity to deliver early breast cancer detection services through Health Centres Assessment of the only existing government health centres (n=3), and an assessment of all community health workers (CHWs) within the project area (n=292). This data was then analysed and followed by a qualitative phase which examined how the PHC capacity can be strengthened for early breast cancer detection. The qualitative data was collected through semi-structured interviews among CHWs (n=14) and key informants (n=11).

The findings from the quantitative phase established that early detection services for breast cancer were limited at the PHC level. The situation analysis established that the PHC system in Kajjansi town council was not oriented towards providing organised breast cancer detection services. The key findings from the qualitative component revealed 1) the need to deliver breast cancer detection services at a community level by leveraging on the existing PHC system and carrying out community outreach 2) engagement with multi-sectoral stakeholders, including the PHC workers, community health workers, community leaders, institutional leaders, government, non-governmental organisations, community members (both men and women).

The quantitative and qualitative findings were then synthesised to inform the development of 'A breast cancer detection' (ABCD) framework. Guided by a socioecological model, the ABCD framework proposes multi-level interventions which can be implemented either individually or holistically towards strengthening the PHC capacity for early breast cancer detection. These interventions include community wide breast cancer education (individual

level); capacity building of CHWs (community level); community outreach (structural level); integrated PHC delivery, establishing breast cancer clinics and capacity building of PHC workers (organisational level); development and implementation of a national cancer control plan and breast cancer guidelines (policy level).

This thesis adds to existing knowledge through the development of a multi-level framework for promoting early breast cancer detection in LICs.

LIST OF OUTPUTS

Publications

- **Ikhile, D.,** Seymour-Smith S., Musoke D. and Gibson L. Using Skype for qualitative interviews: experiences from an empirical study conducted in Uganda. Submitted to *Forum: Qualitative Social Research.*
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- **Ilaboya, D.,** Gibson, L. and Musoke, D., 2018. Perceived barriers to early detection of breast cancer in Wakiso District, Uganda using a socioecological approach. *Globalization and Health,* 14 (9), 1-10.
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Conferences

- **Invited speaker** at Language, Gender and Leadership: Towards a Global, Sustainable Future Conference, 2 – 3 September 2019, Nottingham.
- **Oral presentation** on Inequality and power: experiences of building shared ownership in a global health partnership. Development Studies Association Symposium, 19 December 2018, London.
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- **E-poster presentation** on Investigating the perceived barriers to early detection of breast cancer in Uganda, using a multilevel approach. World Cancer Congress, 31 October – 3 November 2016, Paris, France.

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LIST OF ABBREVIATIONS AND ACRONYMS

ABCD Framework	A Breast Cancer Detection Framework
BCI	Breast Cancer Initiative
BHGI	Breast Health Global Initiative
BSE	Breast self-examination
CBE	Clinical breast examination
CHWs	Community Health Workers
GLOBOCAN	Global Cancer Observatory
HC	Health Centre
HCA	Health Centre Assessment
HICs	High-income Countries
iCCM	Integrated community case management
IEC	Information, Education and Communication
LICs	Low-income Countries
MakSPH	Makerere School of Public Health
MAPH	MA Public Health
MMR	Mixed methodology research
MoU	Memorandum of Understanding
NCCP	National Cancer Control Plan
NCDs	Non-communicable diseases
NGO	Non-governmental organisation
NTU	Nottingham Trent University
PHC	Primary Health Care
PPP	Public-Private Partnership
PTSD	Post-traumatic Stress Disorder
SDGs	Sustainable Development Goals
SSA	sub-Saharan Africa
TNM	Tumour, Nodes, Metastasis
UHC	Universal Health Coverage
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UWOCASO	Uganda Women's Cancer Support Organization
VHT	Village Health Team
WHO	World Health Organisation

CHAPTER ONE

1.0 INTRODUCTION

1.1 My Journey towards a PhD in the Early Detection of Breast Cancer in Uganda

In 2008, I felt a lump in my right breast. At the time, I was studying for my undergraduate degree in Nigeria. The use of the internet was just getting popular, so my first inclination was to check the internet for possible causes of breast lumps. I typed in breast lumps into Google and the result that came up was breast cancer – this scared me. For months, I lived in the torture of [unwarranted] fear until I started to feel pain. At this point, I had no other choice but to inform my parents. We made an appointment with our family doctor who referred us to a specialist at a private hospital. The specialist recommended and conducted a lumpectomy in 2009 after which a biopsy was conducted, and it confirmed it was benign breast tissue- a fibroadenoma. The cost of health services received at the private hospital was expensive. After the surgery, I reflected on my journey towards accessing health care. It made me wonder…what if it was breast cancer and I had delayed for almost a year because of fear? What if my parents could not afford private health care and I could not undergo the surgery? The experience heightened my awareness of breast cancer among women, particularly issues a typical African woman would encounter in detecting breast cancer.

Six years later, in 2014, I started my MA Public Health (MAPH) study at Nottingham Trent University (NTU), UK and embarked on an academic journey towards breast cancer detection research. A key knowledge from the MAPH programme was around multi-level factors influencing health outcomes and I came across this extract during my literature review: *"we will undoubtedly be more successful at preventing [breast cancer] and promoting healing if we approach it through multi-level interventions. Individuals cannot do this alone"* (Schettler 2013 p. 3). This extract resonated with my personal experience and interest that an individual-only approach to health sits within a simplistic paradigm and is insufficient to improve health outcomes. Thus, I adopted a socioecological framework as a theoretical lens to frame my MAPH thesis which focused on investigating the perceived challenges to breast cancer

detection among women in Ssisa sub-county (now Kajjansi Town Council), Uganda (Ilaboya 2015). This study was conducted in 2015.

The findings from this study revealed that the challenges of early detection of breast cancer are complex and comprise interacting individual, organisational, community and policy factors (Ilaboya 2015; Ilaboya, Musoke and Gibson 2018). From the low knowledge amongst the women, to the pervasive myths in the communities, to weak primary health care capacity and lack of a guiding cancer policy at the national level, the challenges were indeed complex. These findings and voices of the women (Figure 1.1) who participated in my MAPH study were too compelling to ignore and motivated my decision for undertaking this PhD study.

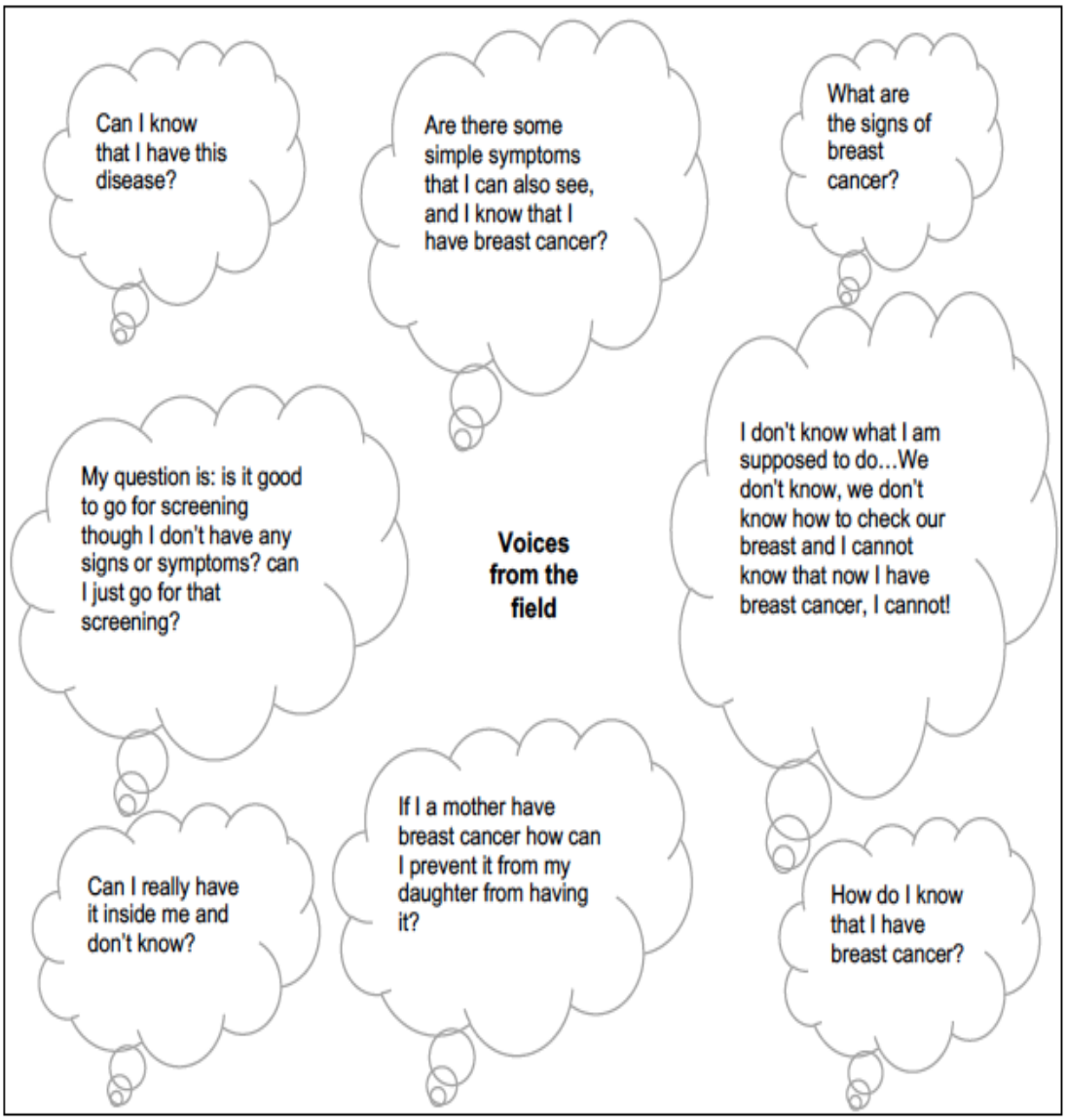

Figure 1.1: Voices of women from the field. Ikhile, Gibson and Wahidin (2019, p. 76)

The motivation and significance of my research interest were further substantiated in 2019 when I held an interview with a community key informant. This key informant was among the women who participated in my MAPH study in 2015. After my interview with her for the PhD, she informed me that because of the insights she gained from my MAPH study in 2015, she was able to advise her sister who had concerns with her breasts:

> *I myself, I have a sister. She started telling us that I'm feeling some things in my breast. Because I did this with you in your research, I didn't tell her anything except to tell her that my dear let us check because I've heard some things about it. So, we found two lumps in her breasts and immediately I took her to the [National] referral hospital. And they have taken the samples from her, so we are waiting. I don't know what will come out but because I've heard it with you, I just told her: you just come to the referral hospital. In fact, she was told by the physician at the [primary health care] health facility: maybe it's because you didn't breastfeed your child and it's the breast milk coming up. So, I told her don't risk your life, you first go and check. (Lilian, NGO representative)*

1.2 Study Background

Breast cancer is the most common cancer affecting women and the leading cause of cancer-related mortality among women globally (Akram et al. 2017; Bray et al. 2018; Torre et al. 2015). The most recent global cancer estimates from the Global Cancer Observatory (GLOBOCAN) showed that in 2018 there were 2,088,849 cases of breast cancer and 626,679 associated deaths globally (Ferlay et al. 2018). The global coverage of breast cancer implies it is not a discriminatory disease as it can affect any woman irrespective of social status, ethnicity, religion or geographical location (Cohen 2014). Once associated with high-income countries (HICs), this disease is now one of the topmost leading cause of deaths among women in low-income countries (LICs) as well (Anderson, Ilbawi and El Saghir 2015; Morse et al. 2014), including countries in the sub-Saharan Africa region (SSA). For instance, Brinton et al. (2014) and Vanderpuye et al. (2017) stated that women in SSA bear the greatest burden of cancer as breast cancer is the most common cause of cancer-related mortality, causing one in five deaths among women in this region.

Although there is no accumulated estimate for breast cancer incidence in SSA, existing statistics presented by GLOBOCAN for Africa for the year 2018 was 168,690 (Ferlay et al. 2018). This figure represents approximately 8% of global breast cancer incidence. While the current estimate for breast cancer incidence in Africa seems low, this could be an under-representation as the true burden of breast cancer for Africa have been difficult to obtain, due to poor monitoring and inadequate cancer registries in this region (Azubuike et al. 2018; Brinton et al. 2014; Pace and Shulman 2016). The seemingly low breast cancer incidence rate in SSA does not correspond with mortality rate across the global community which ranges from approximately 27% in the European region and 22% in the America region to as high as 44% in Africa (Ferlay et al. 2018). This indicates that there is a disparity in mortality rate depending on geographical region. Therefore, this disproportionate higher mortality resulting from breast cancer in Africa makes it a significant public health problem requiring urgent attention.

1.3 Problem Statement

In Uganda, breast cancer incidence has risen about threefold over the past three decades (Galukande et al. 2016; Wabinga et al. 2014). Breast cancer in Uganda now accounts for 12.8% (incidence=2318) of all female cancers in the country (Ferlay et al. 2018), placing it second to cervical cancer. It is also predicted to be the most common non-HIV malignancy among women in the country (Galukande et al. 2016). Like other SSA countries, Uganda has poor survival rates for breast cancer as existing evidence shows that there is a high mortality of 46.4% (mortality=1076) associated with this disease (Ferlay et al. 2018). As with other countries in SSA, this high mortality rate is primarily attributed to late detection usually at stages III and IV which consequently contributes to lower rates of survival (Meacham et al. 2016; Shetty 2014a). Existing bodies of knowledge have shown that breast cancer, like most cancers, is more amenable to treatment if it is detected at early stages (I or II) when it is still localised as opposed to advanced stages (III and IV) which are more difficult to cure (Finkel 2018; McKenzie et al. 2018a; Vanderpuye et al. 2017). However, in Uganda, the majority of breast cancer cases are detected at advanced stages (Galukande, Mirembe and Wabinga 2014; McKenzie et al. 2016).

Early detection strategies such as breast self-examination (BSE) and clinical breast examination (CBE) have been identified as the basis for breast cancer control in SSA and other LICs (Anderson et al. 2008; WHO 2017a). Although these strategies are low cost and recommended for SSA, they are inadequately carried out in most parts of Uganda. The reasons for this are complex and well-articulated in existing literature including weak PHC capacity, low knowledge of breast cancer and its detection, existing double burden of communicable and non-communicable diseases, geographical barriers and funding constraints (Akarolo-Anthony, Ogundiran and Adebamowo 2010; Brinton et al. 2014; Ilaboya 2015; Ilaboya, Gibson and Musoke 2018). The most prominent challenge is the inadequacy in most cases or a complete lack of early detection services for breast cancer at the primary health care (PHC) level (Ilaboya, Gibson and Musoke 2018; Morhason-Bello et al. 2013). Despite the potential of the PHC to promote health and access to health at the community level (Sankaranarayanan et al. 2014), early detection services for breast cancer are not adequately provided at the PHC level in Uganda (Ilaboya 2015; WHO 2014). Specifically, the women who were involved in my MAPH study in 2015 suggested that the PHC capacity in Kajjansi town council is weak to provide breast cancer detection services (Ilaboya 2015). Although the use of PHC for breast cancer detection is gradually being recognised as being appropriate for SSA (Pace et al. 2018; Sankaranarayanan, Ramadas and Qiao 2013), this approach has not been fully explored within the Ugandan context.

Therefore, this study sought to critically examine how the PHC capacity can be strengthened to deliver early breast cancer detection services for women in Kajjansi town council. Since breast cancer is a complex disease (Schettler 2013; Tetteh and Faulkner 2016), it calls for a multidisciplinary approach using a mixed methodology (Baum 2008) comprising of quantitative and qualitative methods. The mixed methodology for this study was based on a sequential design whereby the quantitative and qualitative data collection were conducted in two distinct phases. The quantitative component evaluated the existing PHC capacity to deliver early breast cancer detection services in Kajjansi town council. The qualitative part then focused on the 'what' and the 'how' component to examine context-appropriate evidence on how the existing PHC capacity in the town council can be strengthened to deliver early breast cancer detection services for women. In addition, the complexity of breast cancer

detection challenges necessitated an approach that recognised that these challenges cannot be effectively addressed by focusing on individuals alone. Hence, McLeroy et al.'s (1988) socioecological model of health promotion was adopted as the theoretical underpinning for this study to frame the complex challenges of early breast cancer detection. This is further discussed in section 2.6.1.

1.4 Study Rationale

The need for this study emerged from a previous study I conducted in 2015 which highlighted that a key issue for breast cancer detection in Uganda and most SSA settings is the lack of strong PHC systems which are inadequate in detecting this disease (Ilaboya 2015; Ilaboya, Gibson and Musoke 2018). Strong PHC systems have been identified as a unique platform for facilitating early detection of breast cancer at a community level in SSA countries (Morhason-Bello et al. 2013; Sankaranarayanan et al. 2014). This is because over 90% of contact with the health system occurs at the PHC level (Sankaranarayanan et al. 2014), thus providing the first point of care. For example, in Rwanda, a LIC, the PHC system has been recognised to be effective for providing early breast cancer detection services (Pace et al. 2018). Specifically, Sankaranarayanan et al. (2014) and Bahkali et al. (2015), posit that the PHC is crucial for promoting awareness of early diagnosis to the general population as well as disseminating information regarding breast cancer detection to high-risk populations. Therefore, findings from this research could potentially lead to interventions which would address some or all the challenges associated with breast cancer detection in Kajjansi town council and beyond.

The focus on strengthening the PHC capacity is in alignment with key global commitments and action plans pertaining to the prevention and control of non-communicable diseases (NCDs) including breast cancer. Specifically, the United Nations Political Declaration on the Prevention and Control of NCDs and the World Health Organisation (WHO) high-level commitment to tackle NCDs by 2020 (WHO 2012). Through its *Global Action Plan for the Prevention and Control of NCDs 2013–2020,* the WHO (2013) highlighted the need for strengthening the PHC capacity as a platform for delivering universal health coverage (UHC) in national health systems. Therefore, strengthening the PHC capacity for the early detection of breast cancer is also a component of the UHC mandate as it offers opportunities to expand

universal access to breast cancer services that will, in turn, improve women's health. This would subsequently contribute towards the attainment of the United Nations Sustainable Development Goal (SDG) 3 (Health for all), specifically target 3.4: "to reduce by 2030, premature mortality from non-communicable diseases by one third" and 3.8: to achieve UHC (United Nations 2015).

1.5 Uganda Country Profile

This study focused on Uganda, also known as the Republic of Uganda. Uganda is a landlocked country in the Eastern region of Africa (Figure 1.2) and is bordered by Kenya, Democratic Republic of Congo, South Sudan, Tanzania and Rwanda to the east, west, north, south and southwest respectively (Uganda Bureau of Statistics 2016). The country has a total landmass area of 200,523Km^2 (Uganda Bureau of Statistics 2016). Administratively, Uganda is divided into 4 main administrative regions: Eastern, Western, Northern and Central; 134 districts, and 425 town councils as at 2019 (Uganda Ministry of Local Government 2019). According to the 2019 national population estimates, Uganda had a total population of approximately 40.3 million, with an almost equal distribution of women (50.9%) and men (49.1%) (Uganda Bureau of Statistics 2019). The average life expectancy at birth for women and men in Uganda is 64.5 and 62.8 years respectively (Uganda Bureau of Statistics 2019), meaning women are expected to live for almost two years longer than men. Uganda is classified as a low-income country with a low gross national income per capita less than $1,026 (World Bank Group 2019) which is indicative of a high level of poverty. Although the country achieved its target of halving its poverty level by 2015, this has not been sustainable as the country has a high vulnerability of falling below the poverty line especially among populations living in rural and semi-rural communities (World Bank Group 2018).

Figure 1.2: Map of Uganda showing its borders (United Nations 2002)

1.5.1 The study area- Kajjansi town council

Th study was conducted in Kajjansi town council, formerly known as Ssisa sub-county. Kajjansi town council is a semi-rural community located in Wakiso district in the central region of Uganda. Kajjansi town council was purposively selected because this study built on a previous research conducted in the area around the challenges of early breast cancer detection (Ilaboya 2015). Secondly, the Kampala cancer registry which provides the main estimates for

cancer incidence in the country draws data from Kyadondo county which is located in Wakiso district (Wabinga et al. 2016).

1.6 Study Aims and Questions

The aim of this study was to critically examine how the PHC capacity in Kajjansi town council can be strengthened to deliver early breast cancer detection services for women. Particular focus was on developing practical strategies to address the challenges of breast cancer detection at a PHC level. In addition, the study aimed to further explore the implications of findings for policy and practice relating to breast cancer detection.

Specifically, the study sought to generate answers to the following questions:

1. What is the existing PHC capacity for early breast cancer detection in Kajjansi town council?
2. What practical solutions can be used to address the challenges of early breast cancer detection in Kajjansi town council?
3. How can these solutions improve the PHC capacity to deliver culturally appropriate and context-specific early breast cancer detection services in Kajjansi town council?
4. What are the implications of the findings for local and global breast cancer detection policies and practices?

1.7 Definition of Key Terms

Low-income countries: The World Bank categorises low-income countries as countries earning less than $1,026 Gross National Income per capita (World Bank Group 2019). From a health and development standpoint, LICs are characterised by high poverty rate, low literacy rate, inadequate healthcare facilities, insufficient infrastructure, weak governance system and high dependency on foreign investments and wide inequality gap (Balaam and Dillman 2013).

Sub-Saharan Africa: The World Bank classifies sub-Saharan Africa as 48 countries within the African region. Twenty-three out of these 48 countries are further classified as LICs including Uganda (World Bank Group 2019).

Primary health care: The WHO defines primary health care as the "first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process" (WHO 1978, pp. 3-4).

Early detection: The term early detection is ambiguous. However, this study conceptualises early detection as a non-diagnostic strategy that prompts the discovery of lumps or changes in the breast, which may be indicative of breast cancer. Although early detection does not automatically mean survival, it is based on the premise that detecting breast cancer early will prompt early diagnosis and early treatment (WHO 2007).

1.8 Thesis Structure

Chapter one: Introduction, the current chapter has set the context, background and rationale for this study. It articulates my personal and academic motivations for conducting a study on early detection of breast cancer. Chapter one also outlines the study aims and questions, and provides a description of the study area.

Chapter two: Literature Review provides an in-depth and critical review of the existing literature on breast cancer detection and control, particularly focusing on Uganda and SSA in general. The chapter provides an overview of the global burden of breast cancer and its impacts and discusses appropriate breast cancer detection measures for LICs. The literature review also discusses the use of a socioecological model to frame the challenges of breast cancer detection in Uganda.

Chapter three: Methodology describes the study methodology including the design, research paradigm, data collection methods, data analysis and ethics requirement. It describes and provides a rationale for the use of a sequential explanatory mixed methodology design. The data collection was conducted in two phases- quantitative and qualitative. A description of the two phases and specific methods used are also presented in this chapter. The chapter also provides a detailed description of the study area.

Chapter four: Quantitative findings and discussion chapter presents and discusses findings from the quantitative phase of data collection.

Chapters five, six and seven: Qualitative findings chapters present and discuss findings from the qualitative phase of data collection. The qualitative findings chapters are presented as three separate chapters to aid easy reading.

Chapter eight: Study implications chapter synthesises the key insights from the two phases of data collection to inform the development of a framework to inform the implementation of an early breast cancer detection programme in Uganda. The key emphasis of this chapter is on the practical and policy implications of the study findings and key contributions to knowledge.

Chapter nine: Conclusion and recommendations chapter provides a summary of the study and presents the conclusions. Key recommendations from the study for future research are also highlighted in this concluding chapter.

Lastly, a reflective account of my PhD process and experience is presented.

Chapter Summary

This chapter presents my personal and academic rationales for undertaking a PhD study on how to strengthen the PHC capacity to deliver early breast cancer detection services for women in Kajjansi town council. It provides an overview of breast cancer burden, incidence and mortality in Uganda, and an overview of the challenges around early detection of breast cancer in Uganda. The following chapter, the literature review, provides an in-depth and critical review of breast cancer burden, challenges associated with breast cancer early detection in Uganda, and existing strategies around breast cancer detection in Uganda and other parts of SSA.

CHAPTER TWO

2.0 LITERATURE REVIEW

The aim of this study was to critically examine how the primary health care capacity can be strengthened to deliver early breast cancer detection services for women. Drawing on available literature on breast cancer globally and specifically in Uganda, this chapter analyses, critiques, and synthesises the existing literature on early detection of breast cancer. Where available, the emphasis was placed on literature from and about Uganda and other SSA countries, or other LICs where there is no literature for Uganda and SSA. This chapter specifically includes an overview of breast cancer; the burden of breast cancer in Uganda; early detection strategies for breast cancer in Uganda; and the challenges of early breast cancer detection in Uganda. The challenges are analysed using a socioecological model of health promotion which provides an understanding of how the different challenges interact across multiple levels. The chapter then discusses early breast cancer detection strategies and articulates the value of providing breast cancer detection at the PHC level in SSA. This chapter concludes by highlighting the identified gaps from literature and how this has informed the study questions.

2.1 Literature Review Strategy

The study was multidisciplinary and social science oriented with its focus beyond the epidemiology of breast cancer. Hence, a multidisciplinary approach was also taken towards the literature review search. A summary of the search strategy used in the literature review is described in this section. The literature review search was performed to get a range of academic and non-academic literature using four key electronic databases: NTU Library One, SCOPUS, Google Scholar, Google and reputable cancer websites. The focus was on studies conducted in English or translated to English covering breast cancer in Uganda, SSA and other LICs. For academic literature, NTU Library One was the first point of reference for articles, books and other academic resources. Further literature search was conducted via Scopus and Google Scholar for peer-reviewed articles, while Google was used for non-academic and grey literature. Academic resources on breast cancer or general cancer management with social sciences orientation were purposively selected. Also, breast cancer statistics in Uganda and

other countries were obtained from the following organisation website: World Health Organization, International Agency on Research for Cancer, Global Cancer Observatory and International Association of Cancer Registries.

2.2 Overview of Breast Cancer

Breast cancer is a malignant tumour which occurs in the breast tissue of both men and women. However, it is more common in women (American Cancer Society 2016). Breast cancer can also occur in men, although this is rare, and studies have estimated that less than 1% of total breast cancer incidence occurs in males (Figueroa 2016; Giordano 2018). This study focuses on breast cancer in women due to its higher occurrence among this population. Breast cancer is one of the cellular diseases which results from the rapid growth of the breast cells (American Cancer Society 2016; Pennery 2009). These cellular diseases can either manifest as benign or malignant breast diseases. Common benign breast diseases include breast cysts, fibrocystic breast changes, mastitis, fibroadenoma, and Mondor's disease of the breast (Goehring and Morabia 1997; Shetty 2014b). On the other hand, a malignant breast disease, that is, breast cancer is the type of breast lump that can metastasize, causing damage to other organs of the body (American Cancer Society 2016). According to existing literature, breast cancer is not a single disease but rather a heterogeneous disease (Brinton et al. 2014; Figueroa 2016) with "many anatomic and molecular subtypes, each requiring specific diagnostic and management strategies" (WHO 2017a, p. 7). Although the American Cancer Society (2016) further describes breast cancer as an invasive process, Akram et al. (2017) present that breast cancer can either be invasive or non-invasive depending on the location of cells where the cancer develops. For example, ductal carcinoma in situ, a common non-invasive breast cancer is one which has developed and is situated in the milk ducts, thus regarded as a pre-invasive (Akram et al. 2017; American Cancer Society 2016). Invasive breast cancer is one which spreads into surrounding tissue and can either be invasive lobular carcinoma or invasive ductal carcinoma depending on site where the cancer cell develops (American Cancer Society 2016; Guiu et al. 2014). Other types of invasive breast cancer exist, notably, triple-negative and inflammatory breast cancer which are aggressive types of breast cancer and are more prominent among Black African women (Jones et al. 2014; Robertson et al. 2010; Vanderpuye et al. 2017).

Breast cancer is usually accompanied with signs such as lumps in the breast, changes in the size or shape of the nipple, abnormal discharge from the nipple, asymmetric breast, skin or nipple retraction, blood-stained discharge from the nipple and eczematous changes in the areola, lumps or swelling in the armpit area (WHO 2017a). Although the presence of a lump in the breast is the single most important symptom of breast cancer (Sankaranarayanan, Ramadas and Qiao 2013), not all breast cancer present with lumps, for instance, inflammatory breast cancer (Robertson et al. 2010). Breast cancer is usually accompanied with other signs such as changes in the size or shape of the nipple, abnormal discharge from nipple, lumps or swelling in the armpit area (WHO 2017a). Even though the specific reasons for the development of breast cancer are predominantly unknown, this disease has multifactorial risk factors which are complex (Bosu, Cornelison and Heckman-Stoddard 2014; WHO 2017a) and reportedly vary between and within countries (Brinton et al. 2014). This study broadly classified breast cancer risk factors into non-modifiable and modifiable risk factors. Non-modifiable risk factors are intrinsic factors which predispose a woman to breast cancer. These include genetics disposition, gender, age, history of breast conditions/diseases and reproductive factors (Akarolo-Anthony, Ogundiran and Adebamowo 2010; Lacey et al. 2009; Sun et al. 2017). Gender is one of the single most important risk factors for breast cancer and it is a major predictor of breast cancer incidence (Figueroa 2016), as the likelihood of getting breast cancer is significantly higher for females than males. On the other hand, modifiable risk factors for breast cancer are those socially constructed and extrinsic factors which are dependent on social and environmental conditions. These risk factors broadly include urbanisation, globalisation, westernisation, and population ageing (WHO and UNDP 2019). A detailed analysis of breast cancer risk factors especially those pertaining to SSA women is further discussed in section 2.5.1.

The stage at which breast cancer is detected has a significant impact on the treatment plan and the chances of survival from the disease (American Cancer Society 2019; Iqbal et al. 2015). Breast cancer stages are generally characterised using a numeric system from stages 0-IV except for countries like the UK where TNM classification (Tumour, Nodes, Metastasis) system is used in addition to the numeric system (Cancer Research 2017). Although TNM is the recommended classification for Uganda (Gakwaya et al. 2008), existing literature have

used the numeric system to describe breast cancer stages in Uganda as well as in SSA generally (Galukande, Mirembe and Wabinga 2014; Jedy-Agba et al. 2016; McKenzie, et al. 2018b). As described by Cancer Research UK (2017), the numeric system (0-4) indicates an increasing progression of the disease and decreasing chances of survival. Stage 0 breast cancer such as ductal carcinoma in situ is regarded as a pre-invasive form of breast cancer (Akram et al. 2017) while stage I is the earliest stage of breast cancer with localised tumour size less than or equals to 2cm (Iqbal et al. 2015). The tumour size increases to 2-5cm for stage II while stages III and IV have breast tumours greater than 5cm (Singletary and Connolly 2006) and are referred to as advanced breast cancer (Jørgensen et al. 2017). Anderson et al. (2008) and Balogun and Formenti (2015) explained that advanced breast tumours greater than 5cm may not necessarily be metastatic. According to them, stage III breast cancer with tumour size greater than 5cm is known as locally advanced breast cancer as the breast cancer is still located in the breast and surrounding nodes. However, stage IV breast cancer is one which has become metastatic and is difficult to treat as the cancer has spread beyond the breast and is called metastatic breast cancer (Anderson et al. 2008; Balogun and Formenti 2015). The majority of breast cancer cases in SSA countries are detected at advanced stages (stages III and IV) ranging from 50 to 55% in South Africa (Vanderpuye et al. 2017) and 80% in Uganda (McKenzie et al. 2016) to as high as 98% in Nigeria (McKenzie et al. 2018b) and Tanzania (Black, Hyslop and Richmond 2019). A systematic review of breast cancer stages in Africa revealed that Black African women detect breast cancer at more advanced stages than their white counterparts (Jedy-Agba et al. 2016). The purpose of this study in relation to breast cancer stages is to explore how breast cancer can be detected early, ideally at stages I and II when it is still amenable to successful treatment.

2.3 Breast Cancer Control

Generally, comprehensive cancer control follows a continuum comprising six spectrums: prevention, early detection, diagnosis, treatment, palliative care, survivorship care (WHO 2017a) as indicated in Figure 2.1.

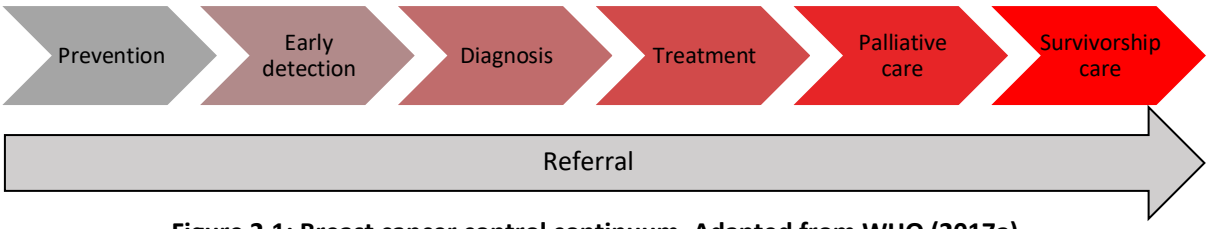

Figure 2.1: Breast cancer control continuum. Adapted from WHO (2017a)

The first spectrum in the breast cancer control continuum is prevention which involves proactive actions taken to reduce the chances of getting the disease. Prevention is a core strategy for NCDs control generally (WHO 2013). Within the context of NCDs management, promotion of healthy lifestyles such as weight management, physical activity, healthy diet, avoiding tobacco use and excessive alcohol intake is crucial for prevention of NCDs (WHO 2013). Preventive interventions for breast cancer include lifestyle behaviour modifications and use of pharmaceutical therapy such as tamoxifen and raloxifene (Akram et al. 2017; Bosu, Cornelison and Heckman-Stoddard 2014) and surgical interventions such as mastectomy (Bosu, Cornelison and Heckman-Stoddard 2014) in extreme cases. In addition, prevention of breast cancer may also be achieved through control of risk factors, for instance, Anderson et al. (2017) show that lifestyle modification may prevent breast cancer. Despite its importance, the effects of lifestyle modification can be limited as impacts will be accrued over a long period of time (Magrath 2007), thereby rendering lifestyle preventive strategies ineffective for breast cancer control. Other publications have argued that generally, preventive strategies for breast cancer are ineffective because risk factors associated with the disease are largely non-modifiable (Anderson, Ilbawi and El Saghir 2015; El Saghir et al. 2011). The cost-effectiveness of breast cancer prevention strategies is also still understudied in LICs (Anderson et al. 2017), making them unpopular in Uganda and SSA in general. That said, early detection has the potential to create a more immediate and substantial effect (Magrath 2007).

Early detection is integral for breast cancer control as it ensures breast cancer is identified and treated at an early stage before the it becomes advanced and difficult to cure (Sivaram et al. 2014; WHO 2017a). The potential of early detection to increase the chances of breast cancer survival, therefore highlights its importance as the focus of this study. There is no clear definition of early detection and it is often used interchangeably with early diagnosis (Finkel

2018; Jafari et al. 2018) or screening (Abuidris et al. 2013; Badal et al. 2018). The interchangeability of early detection with early diagnosis and screening makes it difficult to distinctively define what 'detection' of breast cancer entails. A recent WHO document titled *Guide to Cancer Early Diagnosis* (WHO 2017a) was important in understanding the key strategies for early detection and clarifying differences between early detection, early diagnosis and screening. According to this document, early detection comprises two distinct approaches: early diagnosis and screening. The differences in these two approaches are determined by the type of manifestation of breast cancer symptoms, settings, health system requirements and capacities (WHO 2017a). The WHO (2017a) further defines early diagnosis as the "early identification of cancer in patients who have symptoms of the disease" (p. 8). Screening, on the other hand, is a resource-intensive process that involves evaluation of a target population who are generally asymptomatic (WHO 2017a). This process of screening follows from the invitation of the target population to access timely treatment. Therefore, it can be surmised from this analysis that early detection focuses on the identification of breast cancer cells in symptomatic and asymptomatic populations.

Although studies such as Javari et al. (2018) also refer to early diagnosis as a breast cancer detection measure, their conceptualisation of diagnosis refers to diagnostic techniques which suggest confirmatory evaluation of breast cancer. The use of early diagnosis to confirm breast cancer symptoms suggests that early diagnosis might be distinct from early detection. This distinction has also been recognised by Shetty (2014a) who stated categorically that early detection is distinct from diagnosis. The WHO (2017a) also recognises that screening can either be a diagnostic test or early detection measure, for instance, screening can be used to identify breast cancer symptoms in asymptomatic populations or as a diagnostic test to confirm whether breast symptoms are cancerous. The use of screening for the identification of breast cancer symptoms is further discussed in the next section (2.3.1). The distinction between the three concepts is still blurry and there remains a lack of clarity on the use of early detection, early diagnosis and screening in research and practice. To provide clarity for this study, early detection is conceptualised as a non-diagnostic strategy that prompt the discovery of lumps or changes in the breast, which may be indicative of breast cancer. This conceptualisation of early detection builds on Bonsu and Ncama (2019) who defined early

detection as “the process of noticing or discovering [breast changes]” (p. 7). On the other hand, breast cancer diagnosis refers to definitive or confirmatory tests carried out to confirm or disconfirm that the identified breast disease is breast cancer. The significance of early detection and subsequent early diagnosis for breast cancer control is clear and well documented, as it reduces breast cancer mortality as well as reducing the overall cost of treatment (Brinton et al. 2014; Sivaram et al. 2014; WHO 2017a). Early detection reduces breast cancer mortality by facilitating down-staging, that is a clinical approach for screening cancer at an early stage and prompts early access to treatment (WHO 2017a). Therefore, while early detection is crucial for survival, the availability of effective follow up facilities such as diagnosis and treatment are equally as crucial for optimum outcomes (Sankaranarayanan, Ramadas and Qiao 2013; Vento 2013).

Early diagnosis involves clinical evaluation and pathological examinations of breast cancer through the use of diagnostic imaging (ultrasound, mammography), tissue sampling (biopsy, surgical excision, needle aspiration) (Anderson, Ilbawi and El Saghir 2015; Gong 2014). Breast cancer diagnostic imaging include ultrasound, screening mammography, magnetic resonance imaging, positron-emission tomography (Anderson, Ilbawi and El Saghir 2015; Jafari et al. 2018; Kelly, Shetty and Fregnani 2014). The most commonly used and applicable imaging for LICs are ultrasound and mammography screening (Kelly, Shetty and Fregnani 2014). Although there is evidence to support the effectiveness of breast diagnostic imaging techniques especially mammography, they are limited due to cost intensiveness and low sensitivity (Balogun and Formenti 2015; Corbex, Burton and Sancho-Garnier 2012; El Saghir et al. 2011). Breast cancer diagnosis also includes testing with biochemical tumour markers such as DNAs, mRNAs and microRNAs to determine the type of breast cancer and appropriate course of treatment (Anderson, Ilbawi and El Saghir 2015; Jafari et al. 2018). However, the use of biochemical tumour markers is still regarded as an emerging area for breast cancer diagnostics in LICs (Jafari et al. 2018). The most common strategies for pathological diagnosis that are also recommended for LICs are tissue sampling techniques including fine needle aspiration, core needle biopsy and open surgical biopsy (El Saghir et al. 2011; Gong 2014). Fine needle aspiration is regarded as appropriate for LICs due to its cost-effectiveness but it also requires the technical skill of a cytopathologist thus decreasing its popularity (El Saghir

et al. 2011; Gong 2014). A recommended alternative is the core needle biopsy which is reported to have a higher sensitivity than fine needle aspiration, an accuracy of 98.2% and a specificity of 100% (Vanderpuye, Olopade and Huo 2017). Gong (2014) highlights that the core needle biopsy is more invasive and expensive than the fine needle aspiration. In comparison to the fine needle aspiration and core needle biopsy, an open surgical biopsy is considered the most invasive tissue sampling with a risk of scarring (Gong 2014). Irrespective of their limitations, pathological examinations are important to breast cancer diagnosis for accurate staging and determination of breast cancer type and to inform treatment (Anderson et al. 2008; Gong 2014).

Treatment strategies for breast cancer comprise systemic therapies, radiotherapy and surgical techniques. Surgical techniques for breast cancer treatment include modified radical mastectomy (MRM) and breast conservation surgery (lumpectomy). MRM is the most commonly available treatment in SSA and other LICs as a result of the high incidence of advanced breast cancer in these parts of the world (El Saghir et al. 2011; Vanderpuye, Olopade and Huo 2017). Breast cancer is also treated through radiotherapy and systemic therapies such as chemotherapy, endocrine and targeted therapies (Anderson et al. 2008; Nounou et al. 2015). The surgical treatments are sometimes combined with radiotherapy and systemic therapies to reduce the risk of recurrence (Foerster et al. 2019; Nounou et al. 2015). Breast conservation is a preferred option for breast cancer treatment, but it is not effective in SSA because it is most amenable to early breast cancer stages (American Cancer Society 2019; Olasehinde et al. 2019). This further emphasises the link between breast cancer survival and stage of detection. Breast conservation also requires radiotherapy as adjunct treatment which is not readily available in most SSA settings (El Saghir et al. 2011; Vanderpuye, Olopade and Huo 2017). Alternative treatment methods using plant derivatives such as garlic, turmeric, green tea have also been recorded for breast cancer treatment (Akram et al. 2017; Shareef, Ashraf and Sarfraz 2016) but these are not popular due to limited evidence to support their effectiveness.

In some cases where successful treatment is not feasible, palliative care is required to ease the discomfort of people dying from the disease (Finkel 2018). Palliative care is particularly crucial for LICs where the majority of breast cancer cases are still detected at advanced stages

(El Saghir et al. 2011). Where treatment has been successfully completed, there is still the need for follow-up and what is known as survivorship care within the breast cancer control spectrum. Survivorship care is particularly important to monitor the reoccurrence of breast cancer and also ensure the psychological wellbeing of survivors (Ganz et al. 2013). Breast cancer is a complex health issue as seen from the intricacies surrounding the different spectrums of the breast cancer continuum. These intricacies emphasise that all spectrums need to be harmonised for effective breast cancer control. That is, while early detection is important for breast cancer survival, it would be ineffective without adequate diagnostic and treatment facilities or palliative and survivorship care where appropriate. Thus, breast cancer control can only be effective by taking a holistic approach which considers each component as part of a whole. That said, early detection remains the cornerstone of breast cancer control (WHO 2015) as it determines early access to diagnosis and treatment services.

There is no one size fits it all for breast cancer control, hence, recommended measures for early detection vary across countries depending on resources and capacities. The Breast Health Global Initiative (BHGI), an initiative supported by two international cancer organisations: the Fred Hutchinson Cancer Research Centre and Susan G. Komen in the United States (Anderson et al. 2008; Ganz et al. 2013; Yip et al. 2008) developed four-tiered evidence-based, resource stratified guidelines to guide the provision of breast cancer control services across different settings. The four tiers are based on basic, limited, enhanced and advanced depending on availability of resources (Anderson et al. 2008; Ganz et al. 2013, Yip, et al. 2008). A simplified version of their recommendations applicable to the SSA context (basic and limited) is presented in Table 2.1.

Table 2.1: BHGI table showing recommended resource stratification for breast cancer control in LICs

Breast Cancer Control Continuum	Basic	Limited
Early detection	● Culturally sensitive and linguistically appropriate breast education ● Breast self-examination ● Clinical history ● CBE	● Culturally sensitive and linguistically appropriate outreach ● CBE for high-risk group ● Screening mammography for target group
Early diagnosis	● History of breast cancer ● Physical examination ● CBE ● Tissue sampling	● Ultrasound/diagnostic mammography for positive CBE Fine needle aspiration ● Diagnostic breast ultrasound
Treatment	● MRM (Stages I, II, III) ● Endocrine therapy (Stages I, II, III, IV) ● Supportive therapy (Stage IV) ● Chemotherapy (Stages II, III) ● Total mastectomy (Stage IV)	● Breast-conserving surgery (Stages I, II) ● Chemotherapy (Stages I, IV) ● Radiation therapy (Stages II, III, IV)
Survivorship care	● Health worker education around survivorship and psychosocial care ● Patient and health facility education ● Community awareness of breast cancer survivorship issues ● Peer to peer survivor support	● Psychosocial risk assessment ● Follow up schedules ● Adherence to endocrine therapy ● Emotional and social support by trained professionals

Adapted from Anderson et al. (2008) and Ganz et al. (2013).

2.3.1 Early detection measures for breast cancer

According to the BHGI, early detection measures for breast cancer are broadly categorised into breast awareness, breast examinations and breast screening (Anderson et al. 2008; Yip et al. 2008). Breast awareness is a health promotion approach and the foundation of breast cancer control (Anderson, Ilbawi and El Saghir 2015; Sivaram et al. 2014). This strategy is based on general knowledge of the breast, breast cancer risk factors and its signs and symptoms as well individual familiarity with one's normal breast (Panieri 2012; Sankaranarayanan, Ramadas and Qiao 2013; Thornton and Pillarisetti 2008) to identify changes which may be indicative of breast cancer. According to WHO (2017a), the concept of breast awareness also involves the ability to seek and access prompt care in case of changes

in the breast. It is a recommended approach for SSA due to its cost-effectiveness (Sankaranarayanan, Ramadas and Qiao 2013; Yip et al. 2008). Aside from being cost-effective (Yip et al. 2008), breast awareness was responsible for the significant control of breast cancer and improvement of breast cancer survival in developed countries around 1975 even before the introduction of mammography (Jedy-Agba et al. 2016; Sankaranarayanan 2014). For instance, Sankaranarayanan (2014) states that prior to the popularity of mammography, the achieved gains in breast cancer survival in HICs was substantially attributed to breast awareness. Noteworthy is the advocacy action of activists, the women's health movement, and grassroot organisations in the United States around awareness creation to demystify breast cancer and prompt breast cancer detection (Klawiter 2008; Osuch, et al. 2012). The achieved gains in breast cancer detection and survival reiterates the importance of breast cancer awareness as a foundation for the early detection of breast cancer globally.

Breast examination refers to a non-diagnostic assessment of the breast through self-palpation and general observation (Harvey et al. 1997). In the context of early detection, breast examination can either be Breast Self-Examination (BSE) or Clinical Breast Examination (CBE) (Yip et al. 2008). The distinction between breast awareness and BSE can sometimes be blurred especially as BSE is increasingly being encapsulated as part of breast awareness (Albeshan et al. 2020; Thornton and Pillarisetti 2008) and both terms are used as "getting to know one's breast" (Corbex, Burton and Sancho-Garnier 2012, p. 430). However, BSE involves self-palpation by the woman herself to detect the presence of lumps or other changes in her breast (Corbex, Burton and Sancho-Garnier 2012; Harvey et al. 1997). The effectiveness of BSE in detecting breast cancer and prompting diagnosis is controversial because of a lack of scientific evidence (Albeshan et al. 2020; WHO 2017a). The largest randomised clinical trials about BSE recorded to date were conducted in St Petersburg and Shanghai. After a 5-year follow-up period, both RCTs reported that BSE did not have any impact on breast cancer survival among women (Thomas et al. 2002; Thornton and Pillarisetti 2008). These findings coupled with other shortcomings such as low sensitivity, false-positive, requirement for further tests, and low compliance resulted in BSE being disregarded as an early detection strategy by international organisations including the American Cancer Society (Albeshan et al. 2020; American Cancer Society 2015). According to Shetty (2014b), it makes sense to

implement BSE especially in LICs due to resource constraints, but he also identified compliance as the biggest challenge to BSE implementation. The premise of this study is not that BSE reduces breast cancer mortality, but it has the potential to prompt early detection of breast cancer and subsequent diagnosis and treatment.

A preferred approach to breast awareness and BSE is CBE which refers to a non-diagnostic examination of the breast by a health worker. It is preferable because it involves the physical examination of both breasts, axillae and neck by a trained health worker (Sankaranarayanan, Ramadas and Qiao 2013; Yip et al. 2008). CBE has a higher sensitivity of 40-69% (Albeshan, et al. 2020) and is inexpensive (Anderson, Ilbawi and El Saghir 2015). Similar to BSE, CBE is no longer recommended by the American Cancer Society (American Cancer Society 2015) due to limited studies (RCTs) evaluating its efficacy to reduce breast cancer mortality (Davies and Dimitrievska 2015; Panieri 2012). CBE is also associated with a high rate of false positives and overdiagnosis (Miller and Baines 2011). For instance, a community-based CBE programme in Sudan resulted in the detection of about 85% benign breast tumours (Abuidris et al. 2013). On the other hand, CBE can improve compliance with screening programmes (Miller and Baines 2011) and is still considered beneficial for early detection in LICs (Anderson, Ilbawi and El Saghir 2015; El Saghir et al. 2011; WHO 2017a). In countries where mammography screening is practised, CBE is used as a complementary method for breast cancer detection (Shetty 2014a) and this combination has yielded effective results (Albeshan et al. 2020; Bittencourt and Scarinci 2019). For instance, in Brazil where women are invited for mammography screening once every 2 years, annual CBE was reported to increase participation in the mammography screening programme (Bittencourt and Scarinci 2019). The controversies and shortcomings of breast examinations, both BSE and CBE suggest that a combined approach may be more effective.

With regards to screening, breast screening through mammography is the most common method of breast cancer detection and is regarded as the gold standard for breast cancer detection (Corbex, Burton and Sancho-Garnier 2012; Sankaranarayanan, Ramadas and Qiao 2013). Mammography screening tends to be ambiguous in practice and can be used to mean strategies for early detection or diagnosis as it can be used for both asymptomatic and symptomatic populations, although diagnostic mammogram will only be used for

symptomatic population (Balogun and Formenti 2015; Sankaranarayanan 2014; WHO 2017a). This study focused its analysis on mammography screening for early detection as a strategy to detect breast cancer at a pre-symptomatic stage when it is still amenable to successful treatment (Finkel 2018). The use of mammography screening for early detection can either be organised or opportunistic. Organised screening refers to a centralised population-based programme, whereby invitations are sent to eligible women within a well-defined target population (Sankaranarayanan 2014). Whereas opportunistic breast screening does not require predetermined eligibility and may be sought or performed as part of routine care (Finkel 2018). However, opportunistic screening is only recommended in health systems where there are strong follow-on cancer control services (Finkel 2018; Vento 2013). According to Shetty (2014a), organised screening in SSA is not currently feasible nor would it be feasible in future. This is because screening programmes are usually in line with national guidelines for at risk population and are resource intensive (WHO 2017a). For instance, a study carried out in Ghana showed the cost of mammographic screening intervention to be $12,908 per disability-adjusted life year (DALY) averted, almost ten times the estimated cost for biennial CBE ($1299) and breast awareness through mass media campaigns ($1364) (Zelle et al. 2012).

Gender is one of the two recommended criteria for selecting women for breast cancer screening, with the other being age (Anderson, Ilbawi and El Saghir 2015). For most HICs, women between 50 to 70 years are invited for mammography screening periodically. In the UK, women within this age band receive an automatic invitation for screening every three years (Marmot et al. 2013). In Denmark, another HIC, women aged 50 to 60 years are invited for screening biennially (Jørgensen et al. 2017). The effectiveness of mammography screening is increasingly questioned especially among the younger population as its sensitivity is lower for women less than 50 years of age (Balogun and Formenti 2015). This is a major challenge for mammography screening in Uganda and other SSA where breast cancer occurs in women less than 50 years of age (Galukande and Kiguli-Malwadde 2010; McKenzie et al. 2016; Vanderpuye et al. 2017). The benefits of screening in relation to its potential harm such as overdiagnosis, false-positive results and the possibility of radiation-induced cancer is also an ongoing debate. In 2012, a flagship independent review was commissioned by Cancer Research UK and Department of Health England into the benefits and harms of organised

screening in the UK (Marmot et al. 2013). The report highlights the major benefit and harm as a reduction in breast cancer mortality and overdiagnosis respectively (Marmot et al. 2013). The review panel conclusively stated that "breast screening extends lives" (Marmot et al. 2013, p. 2207). However, due to its other shortcomings particularly in relation to age and cost, it is not considered appropriate for early detection in SSA. An alternative is the use of ultrasound scan which is increasingly being considered as a practical substitute to mammography screening in SSA as it is readily available, cost less per examination, and amenable to the concept of task shifting (Galukande and Kiguli-Malwadde 2010; Tetteh and Faulkner 2016). It is apparent that while international organisations in HICs have discredited BSE and CBE for low sensitivity, with a lack of scientific evidence to support effectiveness, the same can be said of the use of mammography screening among SSA women. Therefore, it can be argued that early detection strategies for breast cancer are contextual and there is no universal gold standard, as the gold standard would differ across countries. Hence, this highlights the need for countries to invest in contextually relevant strategies in promoting sustainable efforts towards the early detection of breast cancer.

2.4 Uganda Health Context

In this section of the literature review, I hone my analysis into the Uganda health system and the burden of breast cancer in the country. Where applicable and to draw robust conclusions, I draw reference from the broader SSA context in the absence of sufficient literature for Uganda. This section begins with a general burden of diseases in Uganda and a description of the Ugandan health system. It is then followed by a detailed review of breast cancer burden and challenges with the detection of the disease in the country.

2.4.1 Uganda health system

Uganda is currently experiencing what is increasingly being referred to as the double burden of diseases (Ministry of Health 2015a; WHO 2017b). This is as a result of the concurrent burden of communicable and non-communicable diseases. Current statistics show that communicable diseases notably, malaria, HIV/AIDs, TB, lower respiratory infections and meningitis dominate and account for about 50% of morbidity and mortality (WHO Africa Region 2016). Conversely, NCDs like cancer, diabetes, cardiovascular diseases, developmental

and mental disorders, violence and injuries are also on the rise (Ministry of Health 2015a). Neglected tropical diseases such as Schistosomiasis also remain a challenge, particularly in rural communities (Ministry of Health 2015a). Uganda has put in place national health policies in order to address the growing burden of diseases in the country and contribute towards universal health coverage (UHC). The policy response to disease management in Uganda is guided by the *National Development Plan II* (Ministry of Health 2015b) and *National Health Policy II* 2010-2020 (Ministry of Health 2010a). These policy documents are aimed at achieving the *Uganda Development Agenda 2040* of a "healthy and productive population that contributes to socio-economic growth and national development" (Ministry of Health 2015b, p. xiv). The Health Sector Development Plan 2015/16-2019/20 has also been developed alongside the *National Development Plan II* and *National Health Policy II* to elaborate on and guide operationalisation of the health agenda in Uganda for the next 5 years (2015-2020) in line with achieving the UHC agenda (Ministry of Health 2015a). The NDP also provides guidelines on how the country intends to achieve the SDGs agenda by 2030. However, none of these policies provides guidance on breast cancer control in the country. Also, a recent analysis of the Uganda health system highlighted a gap in the implementation of these policies (WHO 2017). Therefore, as the country prepares its policy focus and strategy for the next 5 years from 2020 to 2025, (since the polices all run out in 2020) there is an urgent need to ensure that policy responses address the growing burden of breast cancer as well as other cancers and NCDs in general in the country. Future polices should also include a clear pathway for implementation to ensure strategies in the policy documents are translated into practice.

In Uganda's health system, services are provided by both the public and private health sectors. The Ugandan government is the main provider of health services, accounting for approximately 66% of services (WHO 2017b) while the private healthcare sector is categorised as private for-profit and private not for profit (Ministry of Health 2010a; Ministry of Health 2015a). The private not for profit in Uganda includes health facilities affiliated to religious organisations. This sector comprises of four medical bureaus: Uganda Catholic Medical Bureau, Uganda Protestant Medical Bureau, Uganda Muslim Medical Bureau and Uganda Orthodox Medical Bureau (Ministry of Health 2017). In terms of healthcare financing, the latest report from the Uganda National Health Account for the 2015/16 fiscal

year reveals that although the country spends 7.4% of its Gross Domestic Product on health (Ministry of Health n.d.), only 15.7% of this is provided by the government. The remaining percentage of the country's total health expenditure is based on contributions from donor funding and the private sector. 41.7% of the total health expenditure comes from donor funding, while the private sector contributes the remaining 42.6% (Ministry of Health n.d.). It is not surprising that more contribution comes from the private sector as there is a high level of out of pocket expenditure from households and this makes up 41% of the private sector contribution (Ministry of Health n.d.; Ssali 2018). Even though health services became free in Uganda after user fee was abolished in 2001 (WHO 2017), out of pocket expenditure is used to cover costs of laboratory services and purchase of drugs and other essential medical supplies (Nabyonga-Orem et al. 2011). Less than 3% of the total population has access to private medical insurance (Ssali 2018), thus complicating access to universal health care in the country.

Another aspect of the Ugandan health sector is the traditional and contemporary medicine practitioners (TCMP) (Acup et al. 2017; Nakisozi 2014) and traditional healers who provide alternative health care services especially for individuals in rural and semi-rural communities. In SSA and other LICs, these traditional and contemporary medicine practitioners are regarded as an integral aspect of the PHC delivery system due to their accessibility and affordability (Medcalf et al. 2015; Qi 2013). However, their actual contribution to the Ugandan health care system remains unknown (Ministry of Health 2015a). The Government (public) health sector operates a decentralised and tiered system whereby health services are delivered across seven tiers (Figure 2.2) including health centre II, health centre III, health centre IV, district hospitals, regional hospitals and national referral hospitals (Acup et al. 2017; Ministry of Health 2010a). In addition to the health centres, health service delivery at the community in Uganda is supported by Community Health Workers (CHWs), known locally as Village Health Teams (VHTs) in Uganda who make up health centre I (Ministry of Health 2015c).

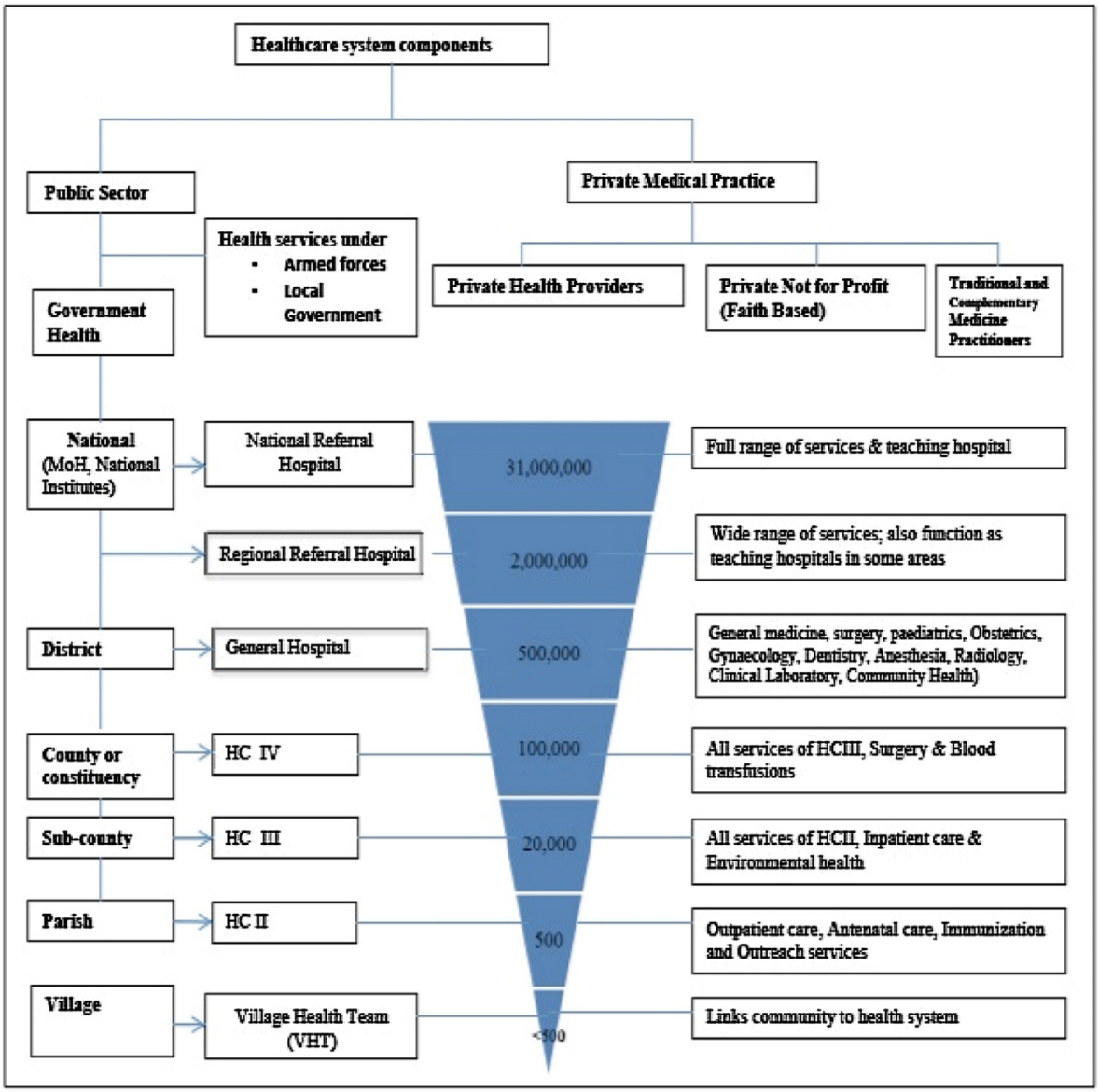

Figure 2.2: Structure of the health care system in Uganda (Acup, et al. 2017, p. 3). Reproduced under a Creative Commons licence CC BY-NC-ND.

Figure 2.1 above from Acup et al. (2017) provides a detailed breakdown of the health care delivery system and catchment population. Similar to countries in SSA like Ghana and Malawi, health care delivery system in Uganda is decentralised (Bulthuis et al. 2020), thus resulting in the hierarchal structure presented in Figure 2.1. Within this decentralised system, responsibilities for health care delivery is placed at the central national level and local district level (Henriksson et al. 2019). At the national level, the public health sector includes the government health facilities governed by the Ministry of Health which is responsible for national health functions such as policy development and priority setting (Ministry of Health 2015a). The delivery of health services by the Ministry of Health is supported by autonomous

and semi-autonomous institutions (Nakisozi 2014; WHO 2017b), for example, the Uganda Cancer Institute (Ministry of Health 2015a). The national referral hospitals occupy the highest tier and serve the entire population (WHO 2017b), estimated at 40.3 million in 2019 (Uganda Bureau of Statistics 2019) with the main functions of providing specialist services, training and research around cancer control in the country and receive referred and walk-in patients. In relation to cancer services, the Uganda Cancer Institute at the Mulago national referral hospital is the only cancer centre in the country (Menon et al. 2017). This clearly demonstrates the inadequate availability of infrastructure for cancer care in the country. The national referral hospital is then followed by regional hospitals which also provide specialist services but not at the same scale as the national referral hospitals (Hjelm et al. 2019). Health service delivery at the regional levels is also managed at the central government level by the Ministry of Health (WHO 2017).

This is then followed by district hospitals and sub-district health centres (HC) I to IV whose responsibilities lie with the district level authorities (Jeppsson 2004; WHO 2017). The district hospitals offer general health services but have a higher portfolio than lower level health centres (Acup et al. 2017). Responsibilities for health care delivery at the district level is further devolved to the health sub-districts who manage HC I to IV (Jeppsson 2004). Health centre IV is a higher level of health centre at the sub-district level which provides general as well as some laboratory and surgical services and is usually responsible for a population of about 100,000 (Acup et al. 2017). Next to this is the HC III which provides both inpatient and outpatient services for a population of approximately 20,000 (WHO 2017b). The first point of contact with the professional health care system is the HC II. This is then followed by the HC I, that is the community health workers (CHWs), who occupy the bottom of the spectrum. Although Acup et al. (2017) estimated the catchment population for HC II and HC I as 500 and less than 500 respectively but a WHO case study on the health system in Uganda shows that the HC II and HC I reach a population of 5000 and up to 1000 respectively (WHO 2017b). Health centres I to IV collectively make up the primary health care system in Uganda (WHO 2017).

Primary health care system in Uganda

The introduction of PHC in Uganda dates back to 1978 through the Alma-Ata Declaration which was endorsed by the WHO member states as a vehicle for delivering health for all by the year 2000 (WHO 2003). In Uganda, the introduction of the PHC concept was regarded as a timely innovation to address the health system challenges such human resources and essential medicines shortages faced by the country as a result of the global recession in the 1970s (Tashobya and Ogwal 2004). Since its introduction, different policies and programmes have been put in place by the Government of Uganda to drive PHC reforms in the country. Notable is the 1995 decentralisation reform (WHO 2017) which was followed by the Local Government Act of 1997, which devolved authority for PHC delivery to district level authorities (Henriksson et al. 2019). As a result, planning, budgeting and health service delivery became the sole responsibility of the district (Jeppsson 2004). The subsequent introduction of health sub-districts to bring health care closer to the community level (Jeppsson 2004) reinforced PHC delivery at this level. Despite, the focus of PHC on comprehensive health care delivery, PHC system in Uganda has been described as fragmented due to lack of coordination and inadequate provision of comprehensive health services (Tashobya and Ogwal 2007). Also, even though PHC delivery in the public sector is provided through the National Minimum Health Care Package, it still suffers from great human resource shortage than other health care delivery systems (Willcox et al. 2015). The human resource shortage is mostly attributed to inadequate resources to support retention and motivate performance. Hence, PHC workers migrate to the private sector or outside of the countries in search of better career opportunities (Willcox et al. 2015). As a result of this gap, the health workforce in Uganda is augmented by the CHWs (Musoke et al. 2019a).

The CHWs programme in Uganda was established by recommendation of the Uganda Health sector strategic plan I 2000/01–2005/06 in response to the continued burden of maternal, neonatal and child mortality (Ministry of Health 2010b). Therefore, it can be inferred that the health needs of women are at the core of CHWs establishment. Beyond, the national health system, the significance of CHWs as being essential for PHC delivery has been stated in the

Alma-Ata declaration (WHO 1978) and reiterated through the Astana declaration on primary health care (WHO 2018a). In addition, the importance of CHWs to health systems around the world has been documented in a recent WHO resolution on *Community Health Workers delivering primary health care: opportunities and challenges* which was adopted at the World Health Assembly in 2019 (WHO 2019). However, the concept of CHWs is not without ambiguity as there is no universal guideline to define the scope of who a CHW is or not (Cometto, et al. 2018). Globally recognised as CHWs, these informal health workers are called by different names in local contexts, for example, accredited social health activists in India (Abdel-All, et al. 2019), agentes polivalentes elementares in Mozambique (Give et al. 2019), volunteer community health workers in Ethiopia (Haile, Yemane and Gebreslassie 2014), rural health motivator in Swaziland (Geldsetzer et al. 2017). The Uganda Health Sector Development Plan (Ministry of Health 2015a) defines CHWs as "community volunteers who are selected by communities to provide correct health information, mobilize communities and provide linkage to health services" (Ministry of Health 2015a, p. x). By this definition, it is evident that CHWs are indeed integral to PHC delivery by linking community members to PHC services, thus serving as a bridge between the community and the health system.

CHWs are integral to the health system in Uganda and other parts of SSA (Cometto et al. 2018; Haile, Yemane and Gebreslassie 2014; Musoke et al. 2018; Olaniran et al. 2017). They are particularly acknowledged for their significant roles in promoting maternal and child health (Haile, Yemane and Gebreslassie 2014; Jarolimova et al. 2018; Olaniran et al. 2017), integrated community case management (iCCM) of childhood diseases (Kalyango et al. 2012; Sunguya et al. 2017) and the management of infectious diseases like HIV and TB (Alamo, et al. 2012, Mwai, et al. 2013, Vaughan, et al. 2015). In Uganda specifically, their role in maternal health promotion and iCCM is well established (Brenner et al. 2017; Kalyango et al. 2012; Mukanga et al. 2012). The role of CHWs in behaviour change communication in relation to access to HIV treatment is also well documented (Alamo et al. 2012; Mwai et al. 2013). In addition, there are emerging evidence to support the potential roles of CHWs in providing health education around NCDs such as mental health in Uganda (Petersen et al. 2011) and SSA in general (Van Ginneken et al. 2013). The role of CHWs in promoting early breast cancer detection have also been identified in South Africa (Wadler et al. 2011) and Rwanda (Pace et

al. 2018). However, there is limited evidence on the potential roles of CHWs in relation to breast cancer in Uganda. CHWs have also been identified as being crucial to the attainment of the health-related SDGs (Olaniran et al. 2017). Furthermore, the Kampala statement (Kampala Statement 2017) published 3 years ago expanded on this stating that CHWs can specifically contribute to the achievement of "SDGs 1 (ending poverty), 2 (ending hunger and ensuring food security), 3 (health and wellbeing), 5 (gender equality), 6 (clean water and sanitation), 10 (reduce inequalities), and 17 (partnerships for global health)" (p. 1). This indicates that CHWs are not only integral to PHC delivery, but they are crucial for the achievement of global health and development agendas.

Uganda is gradually moving towards institutionalising a new cadre of community health workers through its community health extension workers (CHEWs) programme which is intended to bear similarity with the Ethiopian community health programme (Musoke et al. 2020; O'Donovan et al. 2018). The CHEWs programme in Uganda is a new initiative by the Uganda Ministry of Health to train a new cadre of paid community health workers who will serve as linkages in order to strengthen PHC delivery (Ministry of Health 2016). The CHEWs programme was launched in response to a national assessment on CHWs functionality and performance conducted in between 2014 and 2015 (Ministry of Health 2015). Findings from the assessment revealed gaps in CHWs functionality as a result of inadequate training, infrequent incentives and poor supervision, thus CHEWs were recommended to bridge these gaps. However, O'Donovan et al. (2018) and Musoke et al. (2020) raise concerns around clarity on roles and responsibilities of these CHEWs and sustainability of the strategy in light of the existing health system challenges which still plague the CHWs programme. According to the Ministry of Health CHEWs strategy 2015/16 – 2019/20, CHEWs will be predominantly responsible for preventive and promotive health services (Ministry of Health 2016), similar to the current roles of the CHWs. Musoke et al. (2020) reveal that whereas CHWs are selected by members of their communities, it is expected that the CHEWs will be recruited through nomination by their parish and must fulfil certain education (O level education) and age criteria (18-35 years). These criteria raise concerns that CHWs who have the relevant experience and skill set but may not meet the education and age thresholds will not benefit from the CHEWs programme.

Non-communicable Diseases in Uganda

Non-communicable diseases (NCDs) in Uganda are on a steady rise (Ministry of Health 2014a) as is the case globally (Onyilofor 2019). In Uganda, NCDs account for approximately 33% of deaths (WHO 2018). Of these, cardiovascular diseases, cancer, diabetes and chronic respiratory diseases were the most common causes of NCDs related deaths. The Uganda STEPS survey, which provided the first national-level data on NCDs showed that approximately 1 in 10 people aged 18-69 have more than 3 risk factors for NCDs. Although the capacity of the overall public health system in Uganda for NCDs management remains largely unknown, the limited existing studies show critical gaps in areas of health workers capacity, availability of essential medicines and basic technology, insufficient data and funding constraints (Schwartz et al. 2015; Rogers et al. 2018; Schwartz et al. 2014). A recent needs assessment of NCDs prevention and control in the entire 13 referral hospitals, 26 out of 116 general hospitals and 14 out of 170 HC IV showed inadequate specialist human resources, lack of essential medical technologies as required by the WHO, drugs stock out, basic laboratory services, limited specialised NCDs clinics, inadequate guidelines and limited NCDs tracking and monitoring system (Rogers et al. 2018). The main area of strength from the assessment was in the provision of NCDs education, which most of the facilities delivered (Rogers et al. 2018). The authors (Rogers et al. 2018) revealed greater capacities for NCDs at higher level health systems such as regional hospitals in comparison to lower level general hospitals and HC IV. However, the challenges of inadequate essential medicines and other medical supplies are prominent barriers to NCDs service provision at public health facilities in Uganda as revealed by the WHO (2013) and Tusubira et al. (2020). Within lower level PHC system, there is poor readiness and provision of NCDs services in HC II and III in both rural and urban areas as the current PHC system is organised to provide services related to communicable diseases (Katende et al. 2015; Tesema et al. 2020; WHO 2017). The poor PHC capacity to deliver NCDs services strains higher level health systems, thereby rendering the entire health system incapable of adequately managing the rising burden of NCDs in the country. For instance, a case report by Onyilofor (2019) showed that the weekly diabetes clinic at the National referral hospital suffer from frequent drug stock out as drugs are insufficient to cater for increasing number of patients.

Despite the establishment of the programme for the prevention of NCDs unit within the Ministry of Health since 2006 (Schwartz et al. 2015), the progress on NCDs management in Uganda still remains slow especially at the PHC level. A recent review into the integration of NCDs into PHC in the 47 WHO African region countries revealed that none met all 12 recommended progress indicators (Tesema et al. 2020). In order to promote NCDs management and service delivery at the PHC facilities, the Uganda Initiative for the Integration of NCDs recommended an integrated approach which combines NCDs with existing communicable diseases provision (Schwartz et al. 2015). This integrated PHC delivery has been found effective in other parts of the world, such as Canada and Australia (Haque et al. 2020). Another recommendation is task shifting to HC I, that is, the CHWs (Onyilofor 2019) which is already taking place as evident through examples of CHWs involved in NCDs management such as mental health (Petersen et al. 2011) and hypertension (Batte et al. 2020). Although there is a gradual shift towards integrating NCDs services into the PHC system (WHO 2017), greater efforts are required to upscale and sustain existing activities. Such efforts are particularly required in Uganda, where there is a lack of clarity and robust guidelines regarding the organisation and delivery of NCDs services like breast cancer within the PHC system.

2.5 Incidence and Mortality of Breast Cancer in Uganda

There is a global shift in the incidence and prevalence of diseases, especially in LICs where the most prevalent causes of morbidity and mortality were communicable diseases (Cockerham 2007; Finkel 2018). There is now an increasing burden of NCDs, notably cardiovascular diseases, cancer, diabetes and heart diseases in this part of the world. Indeed, cancer is reported to represent a higher burden than HIV, malaria and TB combined (Figure 2.3) in SSA (Schneiden 2020). The graph in Figure 2.3 shows cancer mortality in SSA in relation to mortality from common diseases like HIV/AIDs, malaria and tuberculosis. It is evident that cancer mortality is over three times that of HIV/AIDs, malaria and TB combined. This evidence is a wakeup call for SSA countries where the disease focus is still predominantly on these common diseases.

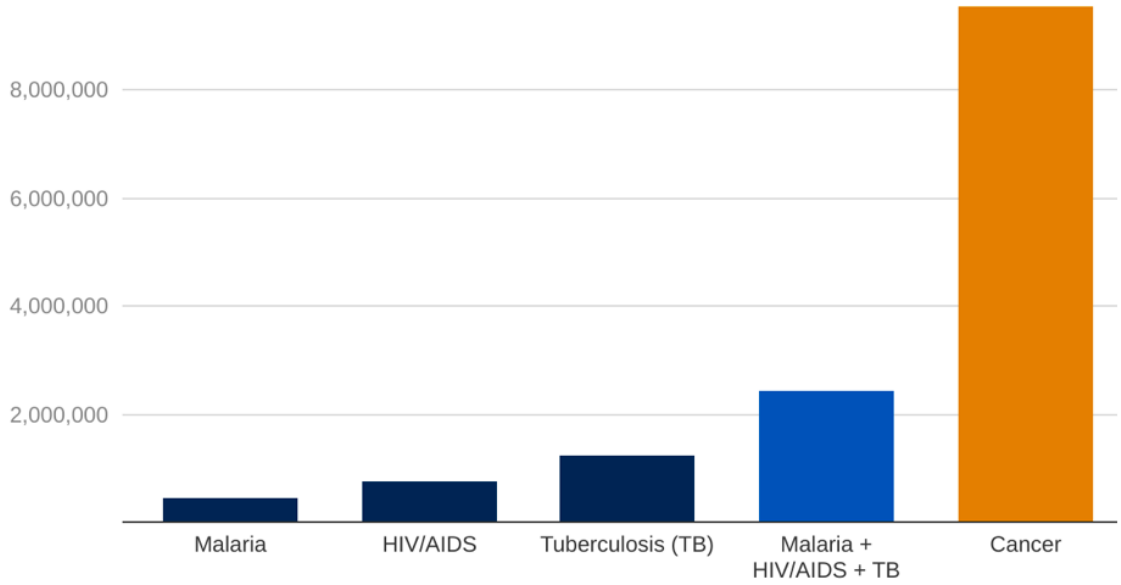

Figure 2.3: Cancer mortality in comparison to mortality from malaria, HIV/AIDs and tuberculosis (Schneiden 2020)

Among the cancers, breast cancer is estimated to be the most common among women globally (Bray et al. 2018; Ferlay et al. 2018). The most recent global cancer statistics as estimated by GLOBOCAN show that breast cancer accounted for 24.2% of all female cancer incidence worldwide (Bray et al. 2018). Although there has been a global decline in breast cancer mortality rates, this is largely as a result of early detection strategies, improvement in treatment and access to quality care in high-income countries (Printz 2017; Hu et al. 2019). However, the reverse is the case in LICs where breast cancer incidence and associated mortality have been on the increase (Printz 2017; Hu et al. 2019). For instance, breast cancer incidence in Uganda has tripled over the past three decades (Galukande et al. 2016; Wabinga, et al. 2014), making it the second most diagnosed cancer among women. The increasing incidence of breast cancer in SSA in contrast with declining rates in LICs and HICs, therefore, indicates geographical disparities associated with this disease.

Breast cancer disparities associated with geographical location manifest in two separate levels, within and outside a given boundary. Perhaps, the greatest disparities within the same location are felt in the United States where Caucasian women have better health outcomes relating to breast cancer care than their African counterparts (Samson et al. 2016). For instance, a publication by the American Cancer Society reports increasing breast cancer incidence among Asians and Black Africans while breast cancer incidence in Caucasians

remained constant (DeSantis et al. 2017). The findings from DeSantis et al. (2017) further indicate the manifestation of racial disparity in breast cancer incidence. In relation to disparities across boundaries, although this disease occurs in all six WHO regions of the world, its incidence is highest in the European and North America regions. Although its incidence is significantly higher in these parts of the world, mortality is very low. For instance, breast cancer incidence and mortality in Northern Europe are 90.1 and 14.1 age standardised rate per 100,000 females respectively. That is a percentage mortality of 15.6%. In contrast, the African region is disproportionately affected by this disease with low incidence but higher rate of mortality. For instance, Eastern Africa has an incidence rate of 29.9 but mortality rate of 15.4, which is 51.5% mortality (Ferlay et al. 2018; Bray et al. 2018). There is also some disparity in breast cancer incidence and mortality rates across the African region. For instance, Western Africa has breast cancer incidence and mortality rates of 37.3 and 17.8, which is 47.7% mortality. This is slightly lower than the percentage mortality in the Eastern Africa region (Ferlay et al. 2018). Furthermore, breast cancer disparities are associated with gender and age. With regards to gender, women are disproportionately affected by breast cancer than men. Breast cancer in men is so uncommon that only 1% of men get breast cancer (Figueroa 2016). In relation to age, a study in Uganda suggests that younger women are likely to survive breast cancer than older women (Galukande, Mirembe and Wabinga 2014).

High mortality rates for breast cancer in Uganda and other SSA is largely attributed to late detection, late clinical presentation, inadequate resources for timely and effective diagnosis and treatment (McKenzie et al. 2018b; Shetty 2014a; Vanderpuye, Olopade and Huo 2017). If detected early and followed by timely access to treatment, breast cancer can be successfully cured using cost-effective measures as the treatment for advanced cases of breast cancer is more expensive with lower rates of survival (Ginsburg et al. 2017; Shetty 2014b). Another reported cause of high mortality in SSA is the aggressiveness of the tumour. Breast cancer in SSA has been shown to be more aggressive as a result of the biological difference in breast cancer between SSA women and their Caucasian counterparts (Amadori et al. 2014; DeSantis et al. 2017). Amadori et al. (2014) found out in their studies to differentiate the biological characteristics of breast cancer among Tanzanian and Italian women that a significant number of breast cancer tumours in the Tanzanian women were more aggressive than those in the

Italian women. There are also limited studies on breast cancer survival and outcomes in SSA women. Perhaps the most extensive study is the African Breast Cancer-Disparities in Outcomes multi-country study involving Uganda, Namibia, South Africa, Zambia and Nigeria, which was designed to evaluate the breast cancer journey from diagnosis through to treatment and survival or death (Foerster et al. 2019; McKenzie et al. 2016). A limitation of this study was that it took a hospital-based approach, so that means only women who have been diagnosed with breast cancer at the hospital were recruited into the study. This hospital-based approach excludes those in the community who for various reasons, were not able to make it to the hospital. High breast cancer survival rates in HICs have been linked to lifestyle improvement, widespread education and awareness, organised early detection, improved diagnostic and treatment infrastructure (Jedy-Agba et al. 2016; Printz 2017; Sankaranarayanan 2014). Of all these factors, early detection is recognised as a crucial driver of breast cancer survival (Ginsburg et al. 2017; Sankaranarayanan 2014). Therefore, the importance of early detection of breast cancer cannot be overemphasised as it can help to mitigate the increasing mortality associated with breast cancer in SSA.

2.5.1 Breast cancer risk factors for Ugandan women

Although there is no single reason for the increasing incidence of breast cancer in SSA, existing literature links this to risk factors which have been broadly categorised as modifiable and no-modifiable risk factors (see section 2.2). In relation to modifiable factors, the increasing incidence of breast cancer in SSA is largely attributed to global trends. Thus, many authors have hypothesised that the recorded increase in incidence is directly linked to aspects of globalisation such as the adoption of western lifestyles, epidemiological transition and changes in environmental trends which increases the prevalence of individual risk factors (Brinton et al. 2014; Duncan et al. 2019; Parkin et al. 2008; Pervaiz and Faisal 2017). “NCDs cross borders in different ways and through different mechanisms, typically involving social and economic changes that have an impact on new lifestyle decisions and changes” (Lang and Caraher 2013, p. 308). In particular, factors such as improvement in socioeconomic profile such as education, income level, aging (Pervaiz and Faisal 2017; Sankaranarayanan and Ferlay 2014) and population growth (Bray et al. 2012) are known to drive demographic and epidemiological transitions. For instance, population growth in Uganda is on a steady increase

at an annual growth rate of 3.4% and the country is considered as fifth in the world in terms of population growth (WHO 2017b). This population growth has a direct correlation with breast cancer incidence in terms of the projected rise in the coming decades (Bray et al. 2012). The adoption of western lifestyles and changes is also believed to have led to a global acceleration of the epidemiological and demographic transition of breast cancer (Bray et al. 2012; Pervaiz and Faisal 2017; Sankaranarayanan and Ferlay 2014).

The World Health Organisation and United Nations Development Programme guidance note for investment cases NCDs prevention and control refer to the adoption of western lifestyle as a modifiable risk factor for cancer and other NCDs (WHO and UNDP 2019). The major four lifestyle risk factors associated with NCDs include tobacco use, physical inactivity, unhealthy diet and harmful use of alcohol (Anderson et al. 2017; WHO and UNDP 2019). Generally, research on modifiable breast cancer risk factors among SSA Africa women is limited (Galukande et al. 2016) but existing studies suggest that physical inactivity which results in obesity is more associated with post-menopausal breast cancer (Ginsburg et al. 2017). Also related to breast cancer modifiable risks are reproductive factors such as age at first full-term birth, parity and breast-feeding practices. Galukande et al. (2016) concluded from a cancer control study carried out in Uganda that longer breastfeeding and early age of first full-term birth reduce the risk of breast cancer. Although a study on breast cancer in SSA suggest that multiparity can be a protective factor against breast cancer among women age 45 and above (Brinton et al. 2014), Galukande et al. (2016) reported that this was not the case from their study conducted among women in Uganda. Other modifiable risk factors associated with breast cancer include post-menopausal hormone replacement therapy, nutrition, use of oral contraceptives and early life exposure to ionising radiation (Anderson et al. 2008; Kelly, Shetty and Fregnani 2014). Generally, these modifiable risk factors can be mitigated through behavioural and lifestyle modifications. As indicated in section 2.3 above, these are preventive measures which may not yield immediate results.

Breast cancer incidence is also directly linked to non-modifiable risk factors, notably sex, age, genetics, history of breast conditions/diseases and family history (Black, Hyslop and Richmond 2019; Brinton et al. 2014; Sun et al. 2017). It is reported that about 25% of all breast cancer cases are linked to family history (Sun et al. 2017). The link between family history and

breast cancer among SSA women is understudied and may also be linked to poor reporting around the history of the disease in SSA (Brinton et al. 2014). Genetics is a high risk for women in SSA as studies have shown that black African women are susceptible to genes causing triple-negative breast cancer which is an aggressive type of breast cancer (Galukande, Mirembe and Wabinga 2014; Vanderpuye et al. 2017). In relation to the history of breast condition/diseases, benign conditions such as fibroadenoma have been documented as a risk factor for breast cancer incidence among Caucasians (Cote et al. 2012; Worsham et al. 2009) but a recent study reported that although fibroadenoma is more common among Black African women, it is not an associated risk factor for breast cancer for them (Shaik et al. 2018).

Age is considered to be an important risk factor for breast cancer (Sun et al. 2017) especially for women in SSA. Existing literature shows that breast cancer in SSA women including those in diaspora tends to occur at a younger age, about 10 to 15 years earlier (Galukande and Kiguli-Malwadde 2010; Vanderpuye et al. 2017) than the global menopausal age of 50 years and above (Galukande and Kiguli-Malwadde 2010). It is estimated that about 70% of SSA women with breast cancer are below the age of 50 years (Black, Hyslop and Richmond 2019). For instance, a study in Uganda showed that the peak age for breast cancer occurrence in women is between 30 to 39 years (Galukande and Kiguli-Malwadde 2010). This varies for other eastern Africa countries where the median age for breast cancer incidence was reported at 44 years and 44.7 years in Kenya and Tanzania respectively (Vanderpuye, et al. 2017). A retrospective study on the epidemiology of breast cancer in another LIC, Central African Republic, also revealed that breast cancer in the country occurs at a younger age (Balekouzou et al. 2016). Out of the 174 cases analysed by Balekouzou et al. (2016), one-third were in the age group 15 to 34 years. This age group of 15 to 34 is the same with Ghana as reported by Naku et al. (2016). The age for Nigeria is slightly higher at an age band of 34 to 45 years (Olasehinde et al. 2019). The reasons for the age discrepancy in breast cancer incidence are still unclear and requires further studies (Black, Hyslop and Richmond 2019; Hjelm et al. 2019). However, this age discrepancy makes breast cancer control a pertinent global health issue of focus especially since women in this age band are in their productive years.

In addition to the modifiable and non-modifiable risk factors, some authors (Black, Hyslop and Richmond 2019; Brinton et al. 2014) further suggest that there might be unique risk factors associated with breast cancer incidence in SSA, particularly in premenopausal women, less than 50 years (Galukande et al. 2016). These risk factors include infectious agents, environmental toxins, cosmetics such as hair relaxers and skin lighteners which is prominent among SSA women. However, Black, Hyslop and Richmond (2019) conclude that these studies are not yet conclusive. Further studies are required to substantiate the influence of these new risk factors in breast cancer incidence among SSA women. Although there are limited studies on the upstream and downstream risk factors among Uganda and general SSA women, there are evidence suggesting that breast cancer are fundamentally driven by the upstream risk factors. Upstream risk factors such as socioeconomic status and geographical location have been shown to cause disparities in breast cancer among women. For instance, literature generally suggest that women in affluent geographical locations (mainly urban centres) with higher socioeconomic status may be more susceptible to certain downstream risks factors especially those linked with westernisation such as physical inactivity, alcohol consumption and smoking (Brinton et al. 2014; Hiatt and Brody 2018; Larsen 2011). The existing evidence are predominantly drawn from HICs like Denmark and the United States (Palmer et al. 2012; Larsen et al. 2011). One study from Uganda did not show any disparity in risk factors based on geographical location (Galukande et al. 2016). Among women with low socioeconomic status, Palmer et al. (2012) showed that breast cancer risk factors are associated with reproductive factors like multiparity. This is consistent with other non-cancer related studies in the SSA region and among Black Africans in diaspora where multiparity has been linked to low socioeconomic status (Omole-Ohonsi and Ashimi 2011; Palmer et al. 2012). These disparities indicate the need for better understanding of how the upstream risk facots influence breast cancer in Uganda and SSA in general. There have also been reported cases where women who are not at risk develop breast cancer. For instance, Kaminska et al. (2015) show that out of the 15784 breast cancer cases from their 2010 Polish epidemiological data, 75 to 80% were not associated with any risk factors. Therefore, this suggests that while prevention is important, early detection is integral as a woman may live a healthy life, that is, live a life free of all modifiable risk factors for breast cancer but still develop the disease.

2.5.2 Impacts of breast cancer on Ugandan women

Breast cancer has significant impacts on the health and wellbeing of a woman as well as the broader community, national health system and national economies. The burden of breast cancer in Uganda is a relatively new challenge for the country. Asides from mortality, which is high for Uganda, breast cancer causes morbidity, thereby affecting the quality of life (Eugenia, Sanganai and Herbert 2019; Olasehinde et al. 2019). The impacts of breast cancer on quality of life is particularly important as breast cancer in SSA women occurs at a younger age (Black, Hyslop and Richmond 2019; Frie et al. 2019; Kohler 2015). Existing literature generally suggests that breast cancer has a significant negative impact on the body image of women, both African and generally, primarily as a result of disfiguration due to mastectomy (Curtis et al. 2014; Eugenia, Sanganai and Herbert 2019; Ganz et al. 2011). "A woman's breasts symbolise both motherhood- central to women's traditional identity and female eroticism [sexuality]- key to sexual attractiveness" (Lantz and Booth 1998, p. 910). Thus, the experience of breast cancer would have individual impacts on women's identity as a mother and their sexuality. For instance, an in-depth interview with fifteen Nigerian women aged 34 to 45 years showed the importance of the breasts to women's identity and how they are regarded as the key feature that tells a man apart from a woman (Olasehinde et al. 2019). The findings from Olaseinde et al.'s (2019) study is consistent with SSA generally (Tetteh and Faulkner 2016). Although contemporary breast cancer treatment such as breast conservation is less likely to result in disfiguration as compared to the aggressive mastectomy practised in SSA, the majority of women in SSA remain at risk for physical disfiguration as mastectomy remain the most common course of treatment for them (El Saghir et al. 2011; Olasehinde et al. 2019). This is because the late stages at which breast cancer is detected among these women call for invasive treatment measures. The risk of physical disfiguration further emphasises the need for breast cancer to be detected at these early stages when it is amenable to less invasive treatment.

Although earlier studies focused on the impacts of breast cancer on the loss of feminine identity and sexuality due to mastectomy, recent studies are now beginning to focus on the wider psychological and social impacts of this disease (Eugenia, Sanganai and Herbert 2019; Olasehinde et al. 2019; Tetteh and Faulkner 2016). In relation to psychological wellbeing,

breast cancer has been associated with increased stress levels among women primarily as a result of breast cancer diagnosis and changes occurring from the treatment of the disease (Curtis et al. 2014; Eugenia, Sanganai and Herbert 2019). Specific psychological impacts of breast cancer from existing studies include anxiety, fear of recurrence and post-traumatic stress disorder (PTSD) (Eugenia, Sanganai and Herbert 2019; Housen et al. 2017). Studies from Nigeria and Zimbabwe have specifically reported that women who have been treated and survived breast cancer expressed anxiety in readjusting to their lifestyle pre breast cancer incidence (Eugenia, Sanganai and Herbert 2019; Olasehinde et al. 2019). Eugenia, Sanganai and Herbert (2019) further established that this experience varied by socioeconomic variables such as age and marital status. PTSD is not only associated with women living in SSA as studies among SSA asylum seekers in Germany also reported that women who had breast cancer experienced PTSD (Grupp et al. 2019). Lastly, Eugenia, Sanganai and Herbert's (2019) study on the impacts of breast cancer on Zimbabwean women established that women who have been diagnosed and treated of breast cancer experience lasting fear of recurrence. Fear of breast cancer recurrence is an important factor for breast cancer control in SSA where the majority of the breast cancer cases are detected late which could also result in the development of recurrent breast cancer especially for breast cancer detected at stage IV (Anderson et al. 2008; Balogun and Formenti 2015).

Other than psychological impacts, breast cancer can also affect sexual intimacy and femininity. The impacts of breast cancer on sexual intimacy and femininity highlights the importance of sociocultural perspectives (Tetteh and Faulkner 2016) particularly taking a gendered approach which focuses on how breast cancer affects social relations between men and women. Breast cancer goes beyond being a female and impacts the interpersonal relations between a woman and a man as well as the wider society. For women in intimate relationships, studies have reported that the experience of breast cancer raise intimacy issues between partners as women have reported decreased sexual libido (Emilee, Ussher and Perz 2010; Masi and Gehlert 2009; Olasehinde et al. 2019). Although there are limited studies on breast cancer and sexual intimacy among SSA women, a study among Nigerians and review among African Americans both revealed that a woman's sexual relationship is negatively impacted after breast cancer treatment due to loss of femininity (Emilee, Ussher and Perz

2010; Olasehinde et al. 2019). Breast cancer also has impacts on gender roles. For instance, in Eugenia, Sanganai and Herbert's (2019) study among Zimbabwean women, they reported that breast cancer treatment weakens a woman and may prevent her from carrying out her domestic chores and other roles as a wife and mother. In relation to social impacts, breast cancer can result in social exclusion due to stigma. For example, a study by Sayed et al. (2019) showed that stigma among Kenyan women in relation to breast cancer is prominent as a result of fear of being socially rejected by family and community. Also, a publication by Novartis (2018) around the burden of breast cancer in Uganda reports that societal norms and even expectation around spousal abandonment results in stigma and even acts as a barrier to seeking care in the case of breast cancer occurrence. The impacts of breast cancer on gender and social relations also manifest as challenges to early breast cancer detection as further discussed in section 2.7.

Economically, breast cancer represents a huge financial burden, as the cost of its management, specifically treatment, is high. This financial burden can be crippling, particularly for LICs, most of which still grapple with high economic impacts of infectious diseases such as malaria and HIV/AIDs (Ginsburg et al. 2017). This is because breast cancer is more expensive to manage as it progresses across the breast cancer control continuum (Cohen et al. 2014; Sun et al. 2018). A review of the cumulative cost of breast cancer treatment by stage of detection shows that the average costs of treating breast cancer increased as follows: $29,724, $39,322, $57,827, $62,108 from stages I to IV respectively (Sun et al. 2018). However, these costs were based on the year 2015 estimates and did not consider any SSA country. Even though there is limited evidence on current estimates for SSA region (Coughlin and Ekwueme 2009), Sun et al. (2018) estimates clearly show that when breast cancer is detected late at stage IV, treatment increases to as much as 109% over stage I. Breast cancer in women, particularly those in SSA also occurs at a prime age when women are contributing significantly to the social and economic lives of their immediate families, communities and nation (Ginsburg et al. 2017). For instance, women who have breast cancer are unable to carry out their livelihood activities due to fatigue (Eugenia, Sanganai and Herbert 2019). This makes breast cancer not only a disease with individual implications, but one that has a wider effect on the community and national wellbeing. Therefore, it can be

surmised that breast cancer not only has physical and psychological implications for individuals but also increases the healthcare spending of a country. However, since early detection has been identified as a cost-effective way to manage breast cancer (Anderson et al. 2008; Yip et al. 2008), there is a need to invest in it as an entry point for cost-effective breast cancer control.

2.6 Early Detection of Breast Cancer in Uganda

The BHGI guidelines and WHO recommendations for the early detection of breast cancer in SSA include breast awareness, BSE and CBE (WHO 2017a; Yip et al. 2008). These recommendations are translated within the Ugandan setting through the *Breast Cancer Guidelines* complied by the Uganda Breast Cancer Working Group (Gakwaya et al. 2008). The recommended strategies for early breast cancer detection by the working group mirror those recommended internationally. Although BSE has been discredited in HICs like the USA, Gakwaya et al. (2008) recommend it as a practical and affordable strategy for early breast cancer detection in Uganda. CBE has also been found to be of high value in a northeastern African country, Sudan, where Abuidris et al. (2013) reported that CBE increased breast cancer detection among asymptomatic women. Screening is not considered appropriate and feasible for Uganda and other LICs as established in section 2.3.1 above, but it is available and mainly offered at private health facilities in urban centres (Black, Hyslop and Richmond 2019). Early detection does not automatically translate to breast cancer survival as early diagnosis and treatment services are still required. Although diagnostic facilities (mammography screening and ultrasound) are available at the national referral hospital (McKenzie et al. 2016) in Uganda, this poses accessibility challenges as the national referral hospital is located in the capital city, Kampala.

A multi-country observational study, the African Breast Cancer-Disparities in Outcomes showed that breast cancer in Uganda is predominantly detected at stages III and IV with a combined percentage of 80% (McKenzie et al. 2016) as shown in Figure 2.4. This is consistent with a review of breast cancer in SSA which shows that up to 80% of breast cancer are diagnosed at stages III and IV among SSA women (Black, Hyslop and Richmond 2019). It also agrees with another study which established that between 40 to 90% of women in SSA

present with stage III breast cancer (Balogun and Formenti 2015). However, the percentage of late-stage breast cancer detection in Uganda is higher than Botswana where 70% of breast cancer are detected at a late stage (Tapela et al. 2018). Stage of breast cancer detection in Uganda is also lower than Nigeria which is estimated between 89.6% to as high as 98% (McKenzie, et al. 2018b, Vanderpuye, Olopade and Huo 2017). A retrospective analytical study of breast cancer patients at the National cancer referral hospital by Galukande, Mirembe and Wabinga (2014) established that women living in rural areas were more likely to present with breast cancer at a late stage than those in urban. Thus urban-rural discrepancy may be due to better access to breast cancer services in urban areas.

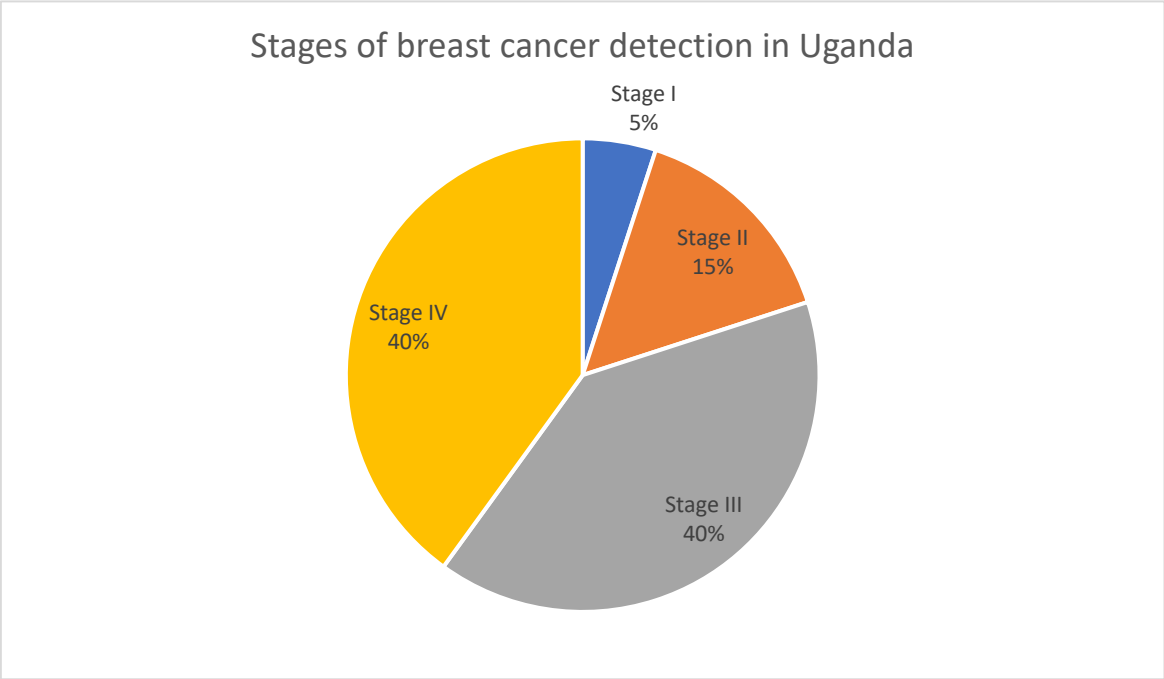

Figure 2.4: Chart showing stages of breast cancer detection in Uganda

The late detection of breast cancer in Uganda and other SSA is attributed to multifactorial and complex factors including low knowledge, weak health systems, inadequate funding, accessibility challenges, inadequate human resources and poverty (Black, Hyslop and Richmond 2019; Gebremariam et al. 2019; Ilaboya 2015; Ilaboya, Gibson and Musoke 2018). By investigating the challenges to early detection of breast cancer in Uganda using a socioecological lens, Ilaboya (2015) previously demonstrated that challenges to breast cancer detection in Uganda are not only complex but interact across multiple levels. Hence, this necessitates an approach that recognises that breast cancer cannot be managed effectively

by focusing on individuals alone. Therefore, a socioecological model was used as a theoretical lens to critically analyse the complexity of early breast cancer detection challenges.

2.6.1 A socioecological model of health promotion

Early attempts by researchers to conceptualise the prevention and management of diseases gave rise to the development of several individual-based models which emphasised changes in behaviours to improve health outcomes (Fitzgibbon, Kong and Tussing-Humphreys 2014). Examples include Rosenstock's (1974) health belief model and the theory of planned behaviour (Ajzen 1985), which focus on individual behaviour as the unit of change. Hence, responses to diseases were reductionistic and individually oriented. Similarly, historical efforts to improve early detection of breast cancer have emphasised this reductionist approach focusing on individualised pathways (Confortini and Krong 2015). However, recent studies have increasingly shown that these individual models are limited in their capacity to effect robust changes as they do not consider the contextual variables that influence health outcomes (Fitzgibbon, Kong and Tussing-Humphreys 2014; Golden and Earp 2012; Paskett et al. 2016). As a result, a number of authors and initiatives have called for an alternative approach for conceptualising the multifactorial determinants of health outcomes. For instance, Rayner (2009) suggests that an [socio]ecological model is required as an alternative to the orthodox models of public health which do not consider the anthropogenic context of health. The WHO publication on the *Social Determinants of Health* (WHO 2008a) was also instrumental in shifting the focus of diseases from biomedical to a multidisciplinary nature. The social determinants of health placed emphasis on a health promotion approach which considers the complex interactions of social, environmental and political factors that shape individual behaviours and determine health outcomes (WHO 2008a). The interactions of these different social, environmental and political factors have been understood in health promotion research using a multilevel approach, for instance, by Golden and Earp (2012). This multilevel approach was adopted for this study as it considers multiple layers of influence in determining health outcomes.

The multilevel approach used for this study is underpinned by McLeroy et al.'s (1988) socioecological model for health promotion which builds on Bronfenbrenner (1977)

ecological framework for human development. The use of a socioecological model transcends the predominant biomedical orientation as it shifts focus from just individual behaviours into a broad range of the other factors that influence health outcomes. Within this model, multiple levels of nested components provide potential points of influence for intrapersonal, interpersonal, organisational, community and policy variables to be addressed holistically (Golden and Earp 2012; McLeroy et al. 1988). Not all research which utilised the socioecological framework as a model followed its rigid interpretations of multiple layers comprising of the intrapersonal, interpersonal, organisational, community and policy. For example, Mahadevan et al. (2014) conceptualisation of the socioecological framework in their study among HIV and comorbidities in African American women comprised individual, interpersonal, environmental, institutional, psychological and overall health outcomes factors. For this research, this model was modified (Figure 2.5) to integrate the structural factors influencing health outcomes. The is because one of its shortcomings identified from a previous study was that there was no consideration for the structural determinants of health within the original model (Ilaboya 2015).The structural factors examined in this study include gender, distance and poverty and how they affect early breast cancer detection. Also, the interpersonal level has been merged with community level as recommended by a previous study (Ilaboya, Gibson and Musoke 2018) which showed that there were visible similarities between interpersonal and community factors. Thus, the levels used in this study include individual, community, organisational, structural and policy factors (Figure 2.5).

According to McLeroy et al.'s (1988) socioecological model, the individual level comprises of the internal agency that enables a woman to detect breast cancer early. These are broadly categorised as knowledge, beliefs, attitude, perception and practices. At the community level, the socioecological model enhances understanding of roles and relationships, resources and support networks that women access which contribute to their perception around breast care and access to care at the community level (Golden and Earp 2012; McLeroy et al. 1988). The organisational level present health system-related factors such as the organisation of the health sector and health service delivery (Ilaboya 2015). The last level of the socioecological model represents the policy dimension. Although presented in concentric circles (Figure 2.5), some studies have shown that the different levels are not distinct but rather interact (Golden

and Earp 2012; Ilaboya, Gibson and Musoke 2018). Therefore, a socioecological model does not only present multiple layers but emphasise the interactions across these layers.

Figure 2.5: Modified socioecological model. Adapted from McLeroy et al. (1988).

While single models have been used, for example, the Health Belief Model to understand the link between low knowledge and breast cancer screening (Atuhairwe et al. 2018; Hall, Pfriemer and Wimberley 2007), there are also some recent publications which conceptualised the challenge of breast cancer using multilevel perspectives. For instance, Ikhile, Gibson and Wahidin (2019) analysed challenges of breast cancer detection in women in Uganda through a structural violence lens. This structural violence lens was used as a double-layered analytical lens to critically examine the drivers of individual and health systems challenges in relation to breast cancer detection. Although a critical perspective, it was used as a top-down model which did not consider the synergy across the layers presented. However, the socioecological model has been widely used in cancer control studies, especially in the United States (English, et al. 2008; Kuo, Mobley and Anselin 2011). This could be because the National Breast and Cervical Cancer Early Detection Program, a national organised breast and cervical screening programme in the United States draws on the socioecological model (Centres for Disease Control and Prevention 2013). Within the SSA context, the socioecological model has been used to study food beliefs and nutrition practices in Ghana (Boatemaa, Badasu and Aikins

2018), and has been used to investigate the challenges to breast cancer detection in Uganda (Ilaboya 2015; Ilaboya, Gibson and Musoke 2018).

2.7 Challenges of Breast Cancer Detection in Uganda

Individual challenges

Breast cancer challenges at the individual level involve factors relating to a woman's knowledge, attitude, beliefs and practices. Knowledge is a major challenge of breast cancer detection among women in SSA countries as shown from existing literature (Finkel 2018; Gebremariam et al. 2019; Ilaboya, Gibson and Musoke 2018). The challenge around knowledge operate in three folds: low knowledge about breast cancer generally, low knowledge of breast cancer risk factors and symptoms; and low knowledge of breast cancer detection measures. In relation to general knowledge, Uganda has one of the lowest rates for breast cancer awareness as it is reported that 1 in 4 women are not aware of breast cancer (McKenzie et al. 2018a). Secondly, a household survey conducted in Kyandondo county, Uganda showed that whereas 91.8% of 414 women had heard of breast cancer, only about half 50.6% knew about the signs and symptoms (Atuhairwe et al. 2018). Similarly, a study in Tanzania revealed that only 30% out of a sample size of 225 knew about the correct risk factors for breast cancer (Morse et al. 2014). In relation to the third fold, a study conducted with women in Kajjansi town council revealed that majority of the women lacked knowledge about breast cancer and how it can be detected (Ilaboya 2015). These evidences point out to the fact that breast cancer knowledge is a broad term, hence there is a need to be explicit about what the knowledge entails in a breast cancer awareness programme. Socioeconomic factors such as age, education and marital status have also been found to have a significant relationship with knowledge of breast cancer and early detection. For instance, Alkhasawneh et al. (2016) suggest that older women over 50 years are less aware of breast cancer early detection measures. They also showed that being married increases awareness (Alkhasawneh et al. 2016). The link to marital status is consistent with a previous study conducted by Ilaboya (2015) which indicated that having a partner could make a woman more knowledgeable about breast cancer and detect breast cancer early.

Another crucial challenge which manifests at an individual level is fear. Generally, women are extremely fearful of breast cancer (Ilaboya 2015; Meacham et al. 2016; Olasehinde et al. 2019). Fear in relation to breast cancer is also manifested in different forms – fear of death, fear of breast cancer itself, fear of breast cancer treatment, fear of loss of sexuality, fear of partner abandonment and fear of losing social support (Ilaboya 2015; Meacham et al. 2016; Olasehinde et al. 2019). Some studies have also revealed that the fear of detecting breast abnormality may prevent a woman from carrying out breast examination or participating in breast cancer detection programmes (Gebremariam et al. 2019; Ilaboya 2015). A qualitative study in Ethiopia confirmed that fear inhibits health-seeking behaviour in relation to breast cancer detection (Gebremariam et al. 2019). However, fear is linked to pervasive myths and misconceptions around breast cancer in Uganda and other SSA countries. For instance, there is a general notion that breast cancer leads to death as shown from studies in Uganda (Ilaboya 2015), Botswana (Mbuka-Ongona and Tumbo 2013), Zambia (Wigginton et al. 2018) and Ghana (Clegg-Lamptey and Hodasi 2007). The consequence of pervasive myths and misconceptions is a reliance on traditional medicine, solely or in addition to western medicines (Sayed et al. 2019; Tetteh and Faulkner 2016). Also, for some women in SSA, breast cancer is not a disease but a curse which could either be as a result of wrongdoing or spiritual attack. This is not unique to breast cancer or cancer generally as unknown diseases in this region of the world are best attributed to fatalistic beliefs where the majority believe that ill or good health is derived from supernatural power (Brinton et al. 2014; Tetteh and Faulkner 2016). These pervasive myths and misconceptions indicate poor health promotion practices for breast cancer detection and are rooted in lack of knowledge and low awareness among SSA women.

Community challenges

At the community level, stigma is a major challenge associated with breast cancer detection as demonstrated by existing literature (Meacham et al. 2016; Olasehinde et al. 2019; Sayed et al. 2019). Stigma is caused by fear of being socially rejected by family and community (Meacham et al. 2016; Sayed et al. 2019). Also, stigma has been found to perpetuate feelings of embarrassment (Ahmad et al. 2001), which could deter women from participating in breast cancer detection programmes and examinations. As a result of stigma, some women also

resort to using traditional medicine (Akuoko et al. 2017). In a study in Uganda, it was revealed that stigma associated with breast cancer does not only deter health-seeking behaviour but also impedes social interactions (Meacham et al. 2016). Meacham et al.'s (2016) study also showed that breast cancer stigma was linked to perception around body image. The link between breast cancer stigma and body image has also been established in a Nigerian study as a barrier to breast cancer detection and control (Olasehinde et al. 2019). Another challenge is the inadequacy of breast cancer organisations to provide accurate health promotion information and guidance (Ilaboya 2015). The available breast cancer organisation is limited and where they exist, are based in the capital city Uganda city thus likely to pose accessibility challenge for women living outside Kampala. For instance, Uganda Women's Cancer Support Organization (UWOCASO), Uganda Cancer Society and Uganda NCDs Alliance. That said, there have been social media publicity of these organisations carrying out events and breast campaigns in other communities outside of Kampala. A critical review of these organisations reveals that whilst they provide general information on their websites to create cancer awareness, the information is provided in English and the websites are not the easiest to navigate (in terms of simplicity of functionality). This is a challenge in a country where average literacy is 62.8% for women living in rural areas and the rate is much lower (24.2%) for women over 60 years (Uganda Bureau of Statistics 2016). This suggests that print-based, or website breast cancer awareness messages may not be suitable for women living in rural and semi-rural areas.

Structural challenges

Structural challenges to breast cancer detection relate to accessibility and sociocultural factors, notably gender. Geographical distance and lack of transportation facilities are common among women living in rural and semi-rural communities in SSA (Dickens et al. 2014; Varela et al. 2019). In a quantitative study in South Africa by Dickens et al. (2014), the effect of distance on breast cancer presentation in a peri-urban setting in South Africa was calculated using GIS. Findings from the study revealed that the risk of delayed presentation for breast cancer was 1.25 folds higher per 30km, thus indicating an association between distance and late breast cancer detection. Distance to health care facilities can also complicate access to health services through poverty (Ginsburg et al. 2017). This is because

the farther the health services are to the community, the longer the distance which implies a woman would have to pay for transportation costs to visit the health facilities. For instance, a previous study revealed that it costs approximately $6 in 2015 for a woman to travel from Kajjansi town council to the national cancer referral hospital in Kampala (Ilaboya, Gibson and Musoke 2018). The cost of accessing breast cancer services is problematic for a country like Uganda where the majority of rural dwellers practice subsistence farming (Uganda Bureau of Statistics 2016) and live below the poverty line of $1.90 daily (World Bank Group 2018). Therefore, the socioeconomic status of women and households in SSA make them more vulnerable to breast cancer mortality (due to delayed detection and difficulty in accessing health care for breast cancer) than their counterparts in other parts of the world.

The prevailing social norms around gender relations further complicates women's vulnerability to breast cancer. Specifically, in many societies in SSA and Uganda, women often adhere to traditional gendered roles such as being the primary caregiver and housewife with men as the breadwinners and decision-makers in the household (Jewkes and Morrell 2010; Musoke et al. 2018; Tetteh and Faulkner 2016). The perpetuation of women's gendered roles as carers can be traced to the development period of 1960-1970 which gave rise to the gendered division of labour within families and relegation of women's roles to being mothers and housewives whose needs are met and taken care of by the head of the family who exercises "benevolent authority and control over its members and resources" (Young 1993, p. 18). Indeed, studies in SSA have shown how the authority men hold over their wives could be a barrier or facilitator to accessing breast cancer detection services (Akuoko et al. 2017; Sayed et al. 2019). The authority exercised by men over the women in their lives is deeply entrenched within the prevailing patriarchal culture in SSA (Global Health Watch in 2017). The prevailing patriarchal structures perpetuate a gender norm around health service delivery whereby a typical SSA woman would not feel comfortable exposing her breasts to a male health worker to palpate. This issue has been previously highlighted among Ugandan women (Ilaboya 2015) and also in Kenya (Sayed et al. 2019). It also extends to other cultural societies, for example, Remennick (2006) identified similar challenges among Muslim women in Israeli communities. This challenge of gender in breast cancer service delivery is not unique to African women as it has been observed in women living in HICs. For instance, a study

conducted by Ahmad et al. (2001) showed that women living in a rural community in Canada preferred being examined by CBE by a female primary care physician. Although 90% (68% male and 32% female) of physicians involved in Ahmad et al.'s (2001) study reported that they could provide screening services to women, male physicians were less likely to perform CBE for women. Therefore, it is apparent that the prevailing patriarchal culture in SSA settings as well as gender norms in health care delivery could impede the empowerment and access of women to early breast cancer detection services.

Organisational challenges

The most significant challenge to the early detection of breast cancer is arguably health system related and has been extensively discussed in existing literature (Black and Richmond 2019; Ginsburg et al. 2017; Morse et al. 2014). One of the prominent findings around breast cancer detection in Uganda is that the existing PHC system is weak to provide early detection services (Ilaboya 2015). Weak in this context is a normative term which describes the inability of the PHC system to provide the WHO recommended services of breast awareness, BSE and CBE for early detection of breast cancer. Ilaboya's (2015) finding was based on a town council in Uganda; however, there is a paucity of data from the Ugandan context to substantiate this finding as there is a paucity of data on breast cancer detection services are available or not available at a PHC level. The challenges within the organisational level are analysed using the WHO health system building blocks which include: health service delivery; health system financing; health workforce; medical products, vaccines and technologies; health information systems; and leadership and governance. However, these health systems challenge cut across both organisational and policy levels. The health service delivery, health workforce and medical products challenges are discussed within the organisational level.

Generally, the organisational challenges of cancer management in LICs is similar for most cancers and include lack of trained personnel, poor health infrastructure for breast cancer detection and lack of diagnostic resources (Finkel 2018; Martin et al. 2019; Tapela et al. 2018). The resultant practice then becomes that women bypass the local PHC centres to the national referral hospital as confirmed in a qualitative study with women in Kajjansi town council (Ilaboya 2015). A retrospective study by Frie et al. (2019) on the health-seeking pathway of

breast cancer patients in Mali also showed that patients who bypassed the PHC centres had considerable shorter diagnosis time (8 days) than those who initially visited the PHC centres (95 days). Almost half of the women in Frie et al.'s (2019) study bypassed PHC centres for tertiary hospitals when seeking care related to breast symptoms for diagnosis. However, in the case of Uganda, bypassing the PHC centres leads to an overwhelming of the national cancer referral hospital. Shortage of skilled health care workers remains one of the major challenges of health improvement in Uganda (Ministry of Health 2015a). Also, where available, human resources are predominantly equipped to address infectious diseases (Galukande and Kiguli-Malwadde 2010). The consequence of this is low knowledge of PHC staff in breast cancer and general NCDs management (Frie et al. 2019; Martin et al. 2019; Mishra et al. 2015). For instance, a recent assessment of general practitioners at the PHC level in Rwanda revealed a substantial gap in knowledge and ability to perform physical cancer examinations (Martin et al. 2019). This is also similar to the case in Mali (Frie et al. 2019) and Botswana (Tapela et al. 2018). Although a study based on qualitative interviews with women and CHWs suggested that the PHC centres staff in Uganda also have low knowledge relating to breast cancer detection (Ilaboya 2015), but there is a dearth of evidence from the PHC staff themselves.

Policy level challenges

The policy level challenges focus on health information system, health care financing and governance. In relation to health information system, although Uganda has two population-based registries in Kampala and Gulu (Wabinga et al. 2016) there is no evidence of a systematic approach for collecting cancer data. A recent systematic review and meta-analysis suggest that cancer statistics in the country are based on hospital data (Adeloye et al. 2018). The implication is that breast cancer incidences at the population level which do not make it to the hospitals are not accounted for. Also, the more established cancer registry which is the Kampala cancer registry only covers one county, Kyadondo as catchment area, and this makes up only 7.6% of the total country's population while Gulu Cancer Registry focuses on the northern part of the country (Wabinga et al. 2016). This inadequate surveillance and poor monitoring system make it difficult to ascertain the number of breast cancer cases in the country per year. Furthermore, the figures collated by the cancer registry which is under-

representative of the true breast cancer burden also makes it difficult to put adequate plans in place at the different levels of the health system for breast cancer control. In terms of governance, Uganda lacks a National Cancer Control Plan (NCCP) or NCDs management plan. In 2005, the World Health Assembly adopted resolution 58.22 which urged its member states to commit to country-specific cancer planning to address the growing burden of cancer nationally and globally (WHO 2005). Although some countries have taken this on board, for instance, Zambia, Ethiopia, Burkina Faso and Ghana (International Cancer Control Partnership 2019), Uganda still lacks a NCCP to address the growing burden of cancer in the country.

The country's strategy for NCDs prevention and control is embedded within the Health Sector Development Plan which highlights three target areas: NCDs prevention, capacity building, and NCDs management (Ministry of Health 2015a). However, it does not provide guidance or how to manage cancer. The only known guidance document for breast cancer control is the Breast Cancer Guidelines put together by a group of experts established in 2003 but there was no indication of inputs or contribution by the government into this document (Gakwaya et al. 2008). This could be an indication of low political will and commitment from the government. That said, Uganda has a specific strategic guideline for the management of cervical cancer (Ministry of Health 2010c). This is, without a doubt, a step in the right direction but one that suggests that cervical cancer is being singled out or prioritised while other cancers including breast cancer are being neglected. Although breast cancer in Uganda is increasingly being recognised, it is not yet regarded a priority as much as cervical cancer which is currently the main focus of national and international funding bodies. Therefore, this inadvertently contributes to the low prioritisation of breast cancer. There are higher recorded incidences of cervical cancer in Uganda than breast cancer (Ferlay et al. 2018). This is most likely due to the close link between cervical cancer and HIV/AIDs (Oluwole and Kraemer 2013). Although the hypothesis associating HIV/AIDs to the attention given to cervical cancer has not been rigorously proven in literature. Unlike cervical cancer whose causes are well defined (Finkel 2018), breast cancer is associated with multiple risk factors as there is no defined cause. Hence, challenges associated with breast cancer detection can be more difficult to overcome compared to cervical cancer (McCurdy et al. 2018).

Funding is another integral component of breast cancer control. Although Uganda operates a user free health care delivery for essential services in the public health facilities through its national minimum health package (WHO 2017b), the country's health care funding like most part of SSA is insufficient to address the growing burden of breast cancer and ensure equitable access to breast cancer control services (Anderson et al. 2011; Ginsburg et al. 2017). As indicated in section 2.4.1, the country has a low health expenditure where only 15.7% is allocated by the national government (Ministry of Health n.d.). Uganda also has a huge reliance on donor funding which contributes 41.7% on health care delivery (Ministry of Health ND). There is limited funding for cancer control in comparison to communicable diseases as about 81% of the existing funding is invested in HIV/AIDs, Malaria and TB management (Essue and Kapiriri 2018; Ministry of Health 2015a). Cohen et al. (2014) partly attribute the limited funding for cancer control to lack of coordinated and robust global and national cancer policies. Furthermore, the lack of coordinated policies is indicative of limited awareness of the significance of the burden of breast cancer and absence of a political will (Cohen et al. 2014; Ikhile, Gibson and Wahidin 2019). From a global governance perspective, there has been minimum funds allocation from national health budgets for breast cancer control as well as allocation in aid from foreign funding agencies (Ginsburg et al. 2017; Shetty 2014b). Ginsburg et al. (2017) specifically revealed that about 5% of global cancer funding is invested in LICs. The majority of health care funding in LICs still focus on HIV/AIDs, maternal health or recently cervical cancer as an add on to existing HIV/AIDs funding (Cohen, et al. 2014). The implication of insufficient government funding is that the government is unable to provide breast cancer detection services at PHC level in the country (Ikhile, Gibson and Wahidin 2019). Therefore, the weak PHC systems around breast cancer detection in Africa can be said to be perpetuated by a lack of public funding. Weak PHC services also lead to overwhelming of the national cancer referral hospital, thus resulting in a vicious cycle where neither the PHC nor national health care systems are efficient to address the growing burden of breast cancer in the country.

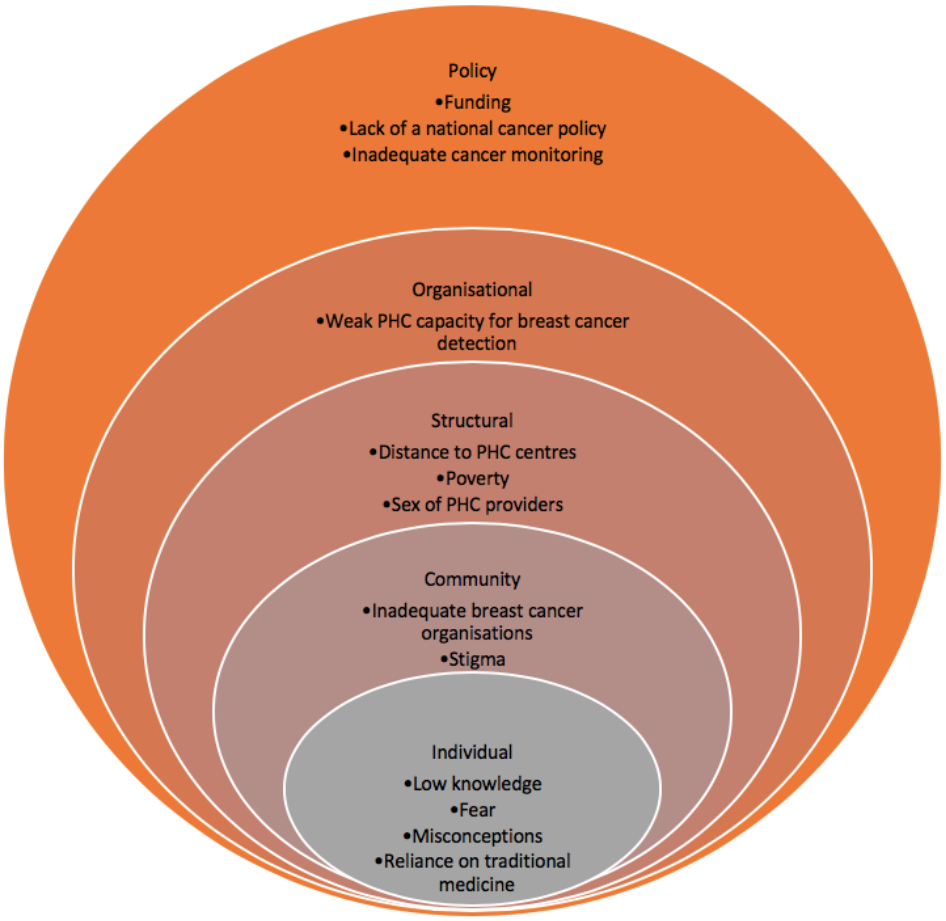

Figure 2.6: Challenges of breast cancer detection in Uganda presented through a socioecological model

It is indeed evident that the challenges of breast cancer detection in Uganda are complex and cut across multiple levels as summarised in Figure 2.6. The analysis of breast cancer detection challenges in this section shows that the challenges interact within and across the different levels. This interaction is essential in order to critique the conceptualisation of breast cancer as an individual problem. Far from being an individual problem, breast cancer is a social problem perpetuated by social constructions and the prevailing neoliberal ideology (Gibson 2014; Lantz and Booth 1998). Ssali (2018) argued that the manifestation of weak and fragmented health care systems in Uganda is symptomatic of the underlying neoliberal ideology underpinning the global health architecture. This position was also evident in Ikhile, Gibson and Wahidin's (2019) critical analysis of the breast cancer detection landscape in Uganda. Their analysis showed that:

> "Women…are deterred or hindered from accessing health care services early, largely because they fear breast cancer and are unaware about how it can be

detected or treated. Women are unaware and fear breast cancer because breast cancer detection services are not available at primary health care level, making the services beyond women's reach financially and geographically. Breast cancer services are unavailable at primary health care level due to low prioritisation of the disease at the national level. Finally, national health priorities are largely driven by global health governance and international funding architecture, which do not adequately support the creation and strengthening of comprehensive cancer programmes" (Ikhile, Gibson and Wahidin 2019, pp. 80-81).

In essence, the multi-level challenges of early breast cancer detection in Uganda are symptomatic of the global health architecture, which is rooted within a neoliberal ideology. From the different challenges analysed, it is also evident that these challenges permeate the overall breast cancer control continuum specifically the treatment spectrum (Foerster et al. 2019; Morse et al. 2014). Hence, findings from this study on early detection could be translated to other spectrums of the breast cancer control continuum.

2.8 Strategies to Promote Early Detection of Breast Cancer in Uganda

A previous study on breast cancer detection in Uganda has suggested that strengthening the PHC capacity can help to address the challenges discussed above (Ilaboya 2015). Although there is a paucity of evidence on the delivery of breast cancer detection services at the PHC level in Uganda, there is a growing acknowledgement of the significance of PHC as a feasible and practical strategy for promoting early detection in SSA and LICs (Bahkali et al. 2015; Sankaranarayanan, Ramadas and Qiao 2013). This is due to its cost-effectiveness, timeliness and proximity to individuals (Dodd et al. 2019; Rubin et al. 2015). PHC has three crucial roles to play in the areas of breast cancer detection: increasing awareness of breast cancer detection, conducting breast cancer detection and helping women navigate the referral system (Sankaranarayanan, Ramadas and Qiao 2013; Tsu et al. 2014). Bahkali et al. (2015) also identify the role of PHC in the context of early detection of breast cancer as promoting breast cancer awareness to the general population as well as disseminating information regarding mammography screening (where available) to high-risk population. There have been some efforts through national non-governmental organisations

(NGOs) such as UWOCASO (Scheel et al. 2017) and the Ugandan NCDs Alliance (Essue and Kapiriri 2018) to create breast cancer awareness in Uganda but none of these have been integrated within the PHC system.

The significance of PHC as a cost-effective and accessible platform for health care delivery is recognised globally as demonstrated through the renewed global commitment to invest in strong PHC systems as a platform for achieving UHC and the health for all agenda. Specifically, through the 2008 World Health Report, *Primary Health Care now more than ever* (WHO 2008b), the SDG 3 agenda (United Nations 2015), Astana Declaration (WHO 2018a) and the recent United Nations High-Level Meeting on UHC (United Nations 2019). It is important to note that these global agendas and commitments emphasise the need to strengthen PHC systems in order to achieve health for all because the original aim of Alma-Ata PHC agenda since its inception in 1978 (WHO 1978) has not necessarily yielded the desired results. However, although PHC was endorsed in 1978 by WHO member countries as a platform to reduce health inequities with an overall aim of achieving UHC (WHO 2003), it has been globally criticised for giving rise to selective or what is commonly referred to as vertical health programmes (Magnussen, Ehiri and Jolly 2004; Tashobya and Ogwal 2004). Specifically, in Uganda, as the idea of PHC was gaining traction among policymakers and health stakeholders, a debate arose around 1980-1983 on whether to invest in selective PHC or comprehensive PHC (Tashobya and Ogwal 2004). A focus on selective PHC was the preferred option which laid the foundation for the uprising of vertical health programmes in the country, thus defeating the true purpose of the PHC concept (Tashobya and Ogwal 2004). However, the renewed commitment to PHC as evidenced through the Astana Declaration (WHO 2018a) now call on PHC system strengthening as a way of achieving comprehensive health care as opposed to investing in vertical programmes.

The use of PHC for providing breast cancer and other female cancer services is gradually emerging in different SSA countries with a particular emphasis on PHC worker-based interventions. For instance, PHC nurses in Zambia are being trained to conduct VIA screening for cervical cancer at the PHC centres (Holme et al. 2017). Also, in Botswana a middle-income country, a recent implementation study focused on training PHC providers to improve early cancer diagnosis and strengthening the referral system (Tapela et al. 2019). Another

upcoming approach is through CHWs led interventions which have been piloted in Brazil (Bittencourt and Scarinci 2019), Sudan (Abuidris et al. 2013) and Rwanda (Pace et al. 2018). These studies have shown that CHWs can be effective in promoting breast cancer awareness and breast examinations in rural communities in SSA. While the emerging literature shows that countries in SSA, as well as other LICs, are beginning to record success in breast cancer detection through PHC interventions, there is a paucity of data on how the PHC capacity in Uganda can be strengthened to provide breast cancer early detection services. Therefore, the aim of this study was to address the following gaps identified from the literature review:

1. Existing PHC capacity for early breast cancer detection in Kajjansi town council
2. Potential solutions to address the challenges of early breast cancer detection in Kajjansi town council
3. PHC interventions to deliver culturally appropriate and context-specific early breast cancer detection services in Kajjansi town council

Chapter Summary

Early detection is an ambiguous concept, but as discussed in this chapter, it is integral for breast cancer control. Early detection strategies analysed in this chapter as appropriate for Uganda include breast awareness, BSE and CBE. An effective early detection programme is one that has a strong referral component to prompt early diagnosis and treatment. The literature review revealed that there are multiple challenges to early detection of breast cancer, and these are complex and inter-related. However, there is an opportunity to address these challenges and promote early breast cancer detection through strengthening the PHC capacity, which was the focus of this study. The next chapter maps out the research process. It describes how the research was conducted in an international setting, the use of mixed methodology and ethical considerations.

CHAPTER THREE

3.0 METHODOLOGY

This chapter describes the use of a mixed methodology for this study. It provides details on the research design, philosophical underpinning, data collection approach and ethical considerations. The aim of this study was to critically examine how the primary health care capacity can be strengthened to promote early detection of breast cancer in women. Particular focus was on developing practical strategies to address the challenges of breast cancer detection at a PHC level. The study further aimed to explore the implication of findings for policy and practice relating to the early detection of breast cancer.

As stated in the previous chapters, the study specifically aimed to answer the following questions:

1. What is the existing PHC capacity for early breast cancer detection in Kajjansi town council?
2. What practical solutions can be used to address the challenges of early breast cancer detection in Kajjansi town council?
3. How can these solutions improve the PHC capacity to deliver culturally appropriate and context-specific early breast cancer detection services in Kajjansi town council?
4. What are the implications of the findings for local and global breast cancer detection policies and practices?

3.1 Mixed Methodology

Mixed methodology research (MMR) also referred to as mixed-methods research combines more than one research approach, data collection methods, data analysis methods, theoretical perspectives or researchers (Creswell 2015; Kara 2015; Shannon-Baker 2016; Tashakkori and Teddlie 2010). The notion of MMR in this study is similar to that of Shannon-Baker (2016), where MMR was conceptualised as the integration of quantitative and qualitative data collection and analysis approaches in a single study. Creswell (2015) expatiates on this concept of integration through his definition of MMR as an:

> "approach to research in the social, behavioural, and health sciences in which the investigator gathers both quantitative ([predominantly] close-ended) and qualitative (open-ended) data, integrates the two, and then draws interpretations based on the combined strengths of both sets of data to understand research problems." (p. 2)

MMR has been in existence for about three decades (Creswell 2015) as a natural complement to the methodological war which has existed between quantitative and qualitative research approaches for over a century (Johnson and Onwuegbuzie 2004). As a result, Johnson, Onwuegbuzie and Turner (2007) and Cameron (2011) also refer to MMR as the third methodological movement that offers an innovative (Cameron 2011), pluralistic (Tashakkori and Teddlie 2010), complementary (Ivankova, Creswell and Stick 2006), creative approach to research (Johnson and Onwuegbuzie 2004; Kara 2015), one that is not restrictive or limiting in the form of data collected. These characteristics have resulted in the increasing recognition of the importance of MMR in multidisciplinary public health research (Fetters, Curry and Creswell 2013; Tashakkori and Teddlie 2010; Vedel et al. 2019). Most importantly, MMR is applicable to the complexity and multidisciplinary nature of health research as it enables a researcher to take a flexible stance which does not consider quantitative and qualitative approaches as dichotomous (Curry and Nunez-Smith 2014; Fetters, Curry and Creswell 2013; Johnson and Onwuegbuzie 2004). This is because MMR does not view quantitative and qualitative approaches as different but rather strives for an integration of both approaches, drawing on their strengths in a single study.

The main simplistic distinction between qualitative and quantitative is that the former focus on qualities while the latter focus on quantity (Bazeley 2013; Kothari 2004). Although quantitative methods produce objective, generalisable data (Johnson, Onwuegbuzie and Turner 2007; Teye 2012), its major limitations are inability to explain behaviours and interpret social realities, perceived lack of depth and subjectivity and exclusion of the participants' voices (Austin and Sutton 2014; Teye 2012; Watkins and Gioia 2015). On the other hand, qualitative research is useful for providing detailed and emergent data (Creswell 2015; Denzin and Lincoln 2012). Furthermore, qualitative research is typically experiential and seeks insights into participants' experiences (Austin and Sutton 2014). However, Creswell (2015) clarifies that these experiences can either be lived or constructed as; what was, what is or

what could be. That is, these experiences are subjective, contextual and not time-bound. Qualitative research is widely criticised for its subjectivity and inability to produce generalisable data (Austin and Sutton 2014; Denzin and Lincoln 2017; Teye 2012). A detailed outline of the distinction between quantitative and qualitative research is provided by Watkins and Gioia (2015) and is presented in Table 3.1. Despite these distinctions, quantitative and qualitative methodologies can be combined to complement each other in a single study (Creswell 2015; Hodgkin 2008; Johnson, Onwuegbuzie and Turner 2007). To show the compatibility of quantitative and qualitative methods, Hodgkin (2008) stated that, "quantitative data may assist in providing the big picture, but it is the personal story, accompanied by thoughts and feelings, that brings depth and texture to the research study" (p. 296). Therefore, MMR was considered appropriate for this study in order to provide breadth through quantitative data collection and provide depth through qualitative data collection.

Table 3.1: Distinction between quantitative and qualitative research. Adapted from Watkins and Gioia (2015).

Focus	Quantitative Research	Qualitative Research
Scope	• Provides prevalence and incidence rates of decisions and actions	• Provides insight into the meanings of decisions and actions
View of the social world	• Provides a broad understanding • Views individual elements of a social phenomena	• Provides in-depth understanding • Provides a holistic view of a social phenomena
Data collection and analysis	• Predominantly closed-ended methods • Fixed	• Open-ended methods • Iterative
Respondents' stance	• Respondents as subjects	• Respondents as active participants
Researchers' position	• Researcher is objective and not an instrument in the research process	• Researcher as an instrument in the research process

From the summary of quantitative and qualitative approaches presented in Table 3.1, it is evident that neither approach is sufficient on its own to capture detailed trends of a situation (Ivankova, Creswell and Stick 2006). In addition to providing data on the breadth and depth of early breast cancer detection, MMR was useful for this study because it provided a practical approach for problem-solving in the real world (Brannen 2005, Watkins and Gioia 2015), in this case, gathering solution to the problem of late breast cancer detection among women in Uganda. Furthermore, Hodgkin (2008) imitated that MMR is suitable for research seeking to influence policy and practice agenda. This builds on Brannen (2005) position that MMR takes a practical approach which combines texts and numbers in solving social problems and consequently informing policy and practice. Although breast cancer detection research has been dominated by quantitative studies with few qualitative studies and even fewer MMR (Akuoko et al. 2017), the use of MMR is gradually increasing as evidenced by emerging publications reporting the use of MMR in breast cancer detection research. For instance, a recent study in Kenya used MMR to assess the knowledge, perceptions and practices of women in relation to breast cancer detection (Sayed et al. 2019). Kohler (2015) also used MMR to understand breast cancer detection preference of women in Malawi. In Ghana, Bonsu and Ncama (2019) used MMR to develop a model for integrating breast cancer detection into palliative care. All three studies highlighted the value of MMR in providing a robust data set for their research. This further buttress the rationale for using MMR in this study to provide breadth and depth to my study findings.

3.1.1 Study design

Despite the strengths of MMR as discussed in the previous section, it has its shortcomings identified from existing literature which include the issue of quality criteria for MMR, more resource intensiveness than single methodological study and integration of the quantitative and qualitative components (Brannen 2005; Halcomb 2019; Plano Clark and Ivankova 2015). Quality in MMR is controversial and has multiple perspectives depending on the discipline, audience, funding bodies, paradigmatic positions (Clark and Ivankova 2015). Tashakkori (2009) posit that assessing quality in MMR is complicated as it involves the integration of two different data sets. However, Bryman (2008) and O'Cathain (2010) recommend that the quantitative and qualitative components can be assessed separately as a starting point and a

combined framework can be used to assess the MMR component. However, there is no established framework for assessing MMR as yet (Clark and Ivankova 2015; Halcomb 2019). Another major issue with MMR is the lack of clarity on how the quantitative and qualitative components are integrated (Bryman 2007; Fetters, Curry and Creswell 2013; Halcomb 2019). Specifically, Bryman (2007) reported that MMR researchers still treat the quantitative and qualitative components of their research as separate entities and do not always tie them together for reasons which range from methodological preference, writing for a specific audience, researcher skills, philosophical orientation. However, a recommended strategy in addressing this issue of quality and integration challenges is the need for rigour through clarity on the type of MMR design used (Aramo-Immonen 2011; Creswell 2007). Although MMR is typically recognised as a research strategy, it has also been considered as a type of research design (Brannen 2005; Ivankova, Creswell and Stick 2006). As a research design it can stand on its own right within which other strategies (quantitative and qualitative) are used of data collection. However, as a strategy, MMR can be used within other research designs such as ethnography and case study (Brannen 2005). According to Greene (2007) and Johnson and Onwuegbuzie (2004), quantitative and qualitative data are integrated through triangulation, complementarity, initiation, development of methods, and expansion. Based on these, MMR authors have attempted to develop different MMR designs.

Over forty different MMR designs exist (Ivankova, Creswell and Stick 2006; Tashakkori and Teddlie 2010) which can be broadly categorised most as convergent, sequential explanatory, sequential exploratory and advanced MMR designs (Creswell 2015). The use of MMR to triangulate or complement typically draws on concurrent or convergent MMR design which involves the collection of quantitative and qualitative data separately and then integrating the findings in order to triangulate (Creswell 2015; Watkins and Gioia 2015). This is the most common type of MMR design. For instance, a recent study on breast cancer knowledge and perceptions in Kenya used a convergent MMR (Sayed et al. 2019). Whereas, advanced or MMR design are complex studies such as intervention, social justice or multi-stage evaluation study designs (Fetters, Curry and Creswell 2013). In sequential MMR design, the quantitative and qualitative data are conducted in two distinct phases (Creswell 2007). The main purpose of sequential MMR is for both components to be integrated in a developmental, initiation or

expansion way (Ivankova and Clark 2018). The sequential design is exploratory or explanatory depending on which data collection comes first (Johnson, Onwuegbuzie and Turner 2007; Schoonenboom and Johnson 2017). In the sequential exploratory design, qualitative data is collected in the first phase and subsequently followed by quantitative data collection and analysis. In an explanatory design, quantitative data is first conducted and analysed and subsequently followed by the qualitative process (Creswell 2007; Ivankova, Creswell and Stick 2006; Schoonenboom and Johnson 2017). A sequential explanatory design was adopted for this study because of the opportunity it offers in being able to elaborate on quantitative findings through the qualitative data collection. The strength of the sequential explanatory design is that it enhances clarity as data collection are conducted and presented in two different phases (Creswell 2007). However, it can also be time-consuming especially when the design is developmental where the researcher cannot proceed to the qualitative phase until the quantitative is collected, analysed and interpreted (Creswell 2007; Plano Clark and Ivankova 2015).

The application of an explanatory design is well grounded in social sciences and behavioural sciences research (Creswell and Creswell 2018; Ivankova 2004) and has been used across various disciples such as health promotion (Baheiraei et al. 2014), clinical health research (Carr 2009) and education (Ivankova, Creswell and Stick 2006). Specifically, explanatory design has been used in past doctoral studies in Psychology (De Motte 2015) and Education (Ivankova 2004). However, this study is the first known study to apply a sequential explanatory MMR design to breast cancer detection in a SSA country. The two key considerations in sequential MMR design are the dominance of the quantitative and qualitative components, and point of integration (Ivankova, Creswell and Stick 2006; Schoonenboom and Johnson 2017). Qualitative and quantitative components can have equal dominance, or one component can drive the other (Schoonenboom and Johnson 2017). Creswell (2007) suggest that in an explanatory sequential mixed methods design, priority is on the quantitative study. However, Plano Clark and Ivankova's (2015) position is that priority can be given to either the quantitative or qualitative depending on the study focus. The dominance of the two components has given rise to different notations which are used to

simplify and also summarise the order and dominance of the MMR study. The applicable notations for sequential MMR are presented in Figure 3.1.

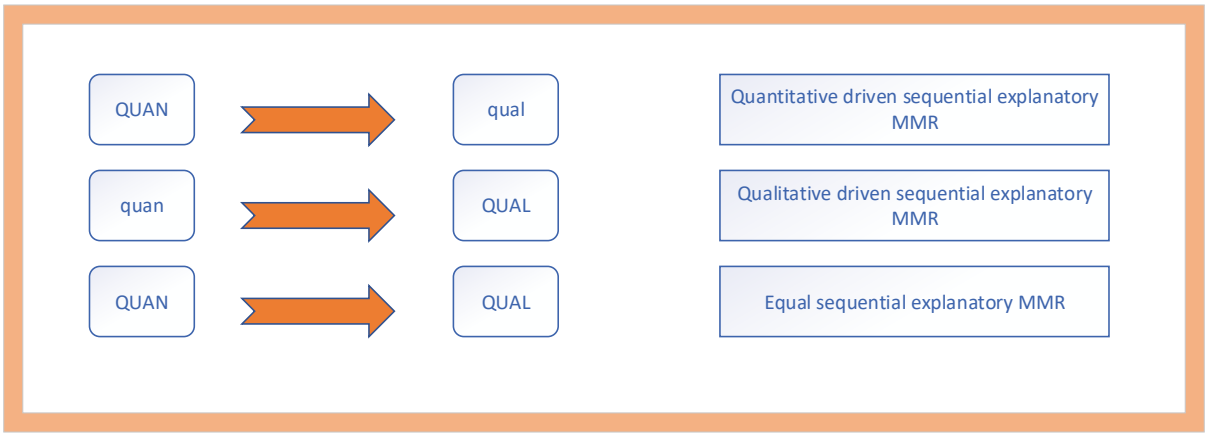

Figure 3.1: Sequential explanatory MMR notations. Adapted from (Creswell 2007; Schoonenboom and Johnson 2017)

Schoonenboom and Johnson (2017) regard the point of integration as the most important consideration in MMR design. Possible integrating points for sequential design could be at the point of participant selection, point of qualitative protocol design which is developed from the quantitative findings and during discussion (Ivankova, Creswell and Stick 2006; Schoonenboom and Johnson 2017). The MMR approach for this study followed a developmental explanatory sequence (Nastasi, Hitchcock and Brown 2010) as the quantitative phase sought to inform development of the qualitative phase (Figure 3.1). That is, data collection was done in sequence with the quantitative data collected first and analysed to inform collection of qualitative data. This was essential because an understanding of the existing PHC capacity for early breast cancer detection was required to guide the qualitative data collection. Furthermore, priority was given to the qualitative component, so, the MMR design for this study was qualitatively driven. While the quantitative data provided a foundation and informed what questions should be asked (detailed in Section 4.4), the main body of evidence which addressed the research aims were gathered from the qualitative process. As presented by Plano Clark and Ivankova (2015), the integration occurred at two points. The first point of integration was at the end of the quantitative phase and beginning of the qualitative phase, during the design of the qualitative data collection tool (this is further described in Section 4.4). Secondly, the quantitative and qualitative phases

were integrated at a discussion level (Figure 3.2). Although the results are presented and discussed separately, the insights from both phases were synthesised in the study implications chapter (Chapter 8.0). The quantitative and qualitative data collection which make up the two phases of this study focused on:

- Phase one (quantitative): which was to evaluate the existing PHC capacity to deliver early breast cancer detection services in Kajjansi town council; and
- Phase 2 two (qualitative): which was to examine how the PHC capacity in Kajjansi town council can be strengthened to deliver culturally appropriate and context-specific strategies for early breast cancer detection for women.

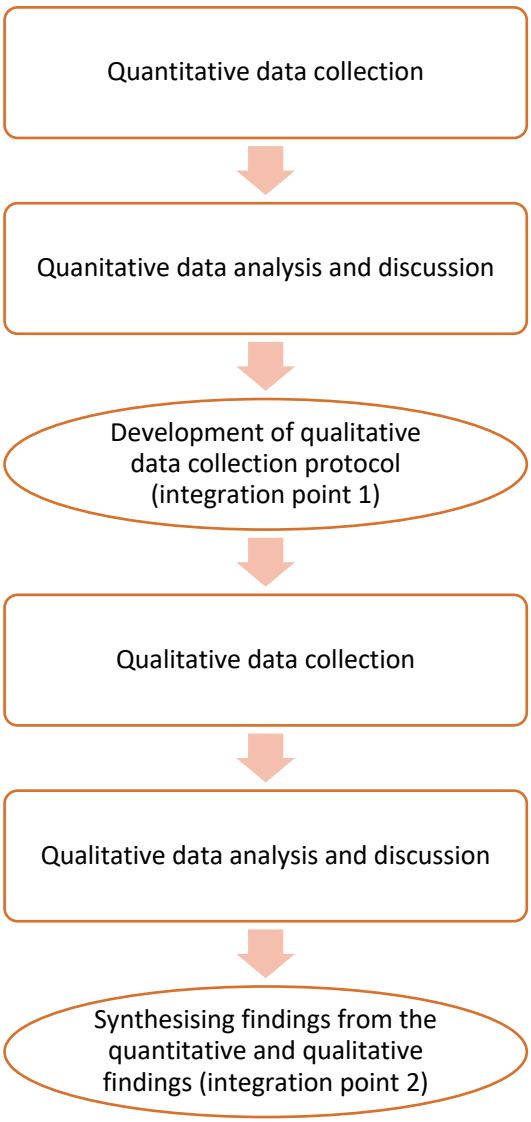

Figure 3.2: A visual model of the Sequential explanatory MMR design for this study

3.1.2 Mixed methodology research paradigm

This section presents the paradigm, that is, the ontology and epistemology underpinning my choice of MMR. Paradigms refer to human constructions which define a researcher worldview and therefore guide research actions (Denzin and Lincoln 2017). Creswell and Creswell (2018) further refer to it as a philosophical orientation, while Brannen (2005) describes it as a key driver of a researcher's choice of methodology. The philosophical underpinnings of qualitative and quantitative approaches are presented as competing paradigms (Slawecki 2018; Watkins and Gioia 2015). Quantitative research is based on a positivist/postpositivist paradigm that contends that the social researcher is distant from the social phenomenon being researched (Tashakkori and Teddlie 2010; Watkins and Gioia 2015). Therefore, according to a quantitative paradigm, an objective, singular reality exists which is predominantly descriptive in nature (Guba, Lincoln and Denzin 1994; Slawecki 2018). In contrast to this is the qualitative paradigm occupying the other end of the continuum. Qualitative paradigm embraces the constructivist notion of a subjective, value-laden, multiple realities of qualitative approach, which is more interpretive in nature (Denzin and Lincoln 2017; Taylor 2005). Both approaches have been in a paradigm war which has engendered what Johnson and Onwuegbuzie (2004) and Hodgkin (2008) refer to as the incompatibility thesis. This incompatibility thesis posits that "qualitative and quantitative research paradigms, including their associated methods, cannot and should not be mixed" (Johnson and Onwuegbuzie 2004, p. 14). However, as a result of the paradigmatic differences, strengths and weaknesses of both quantitative and qualitative approaches, MMR has gained visibility as an approach for integrating these two approaches in a single research.

Alternative paradigms have also emerged for MMR in response to the polarisation of positivist and constructivism, for example, critical realism, pragmatism, transformative-emancipation and dialectics (Shannon-Baker 2016; Tashakkori and Teddlie 2010). Dialectics calls for the use of multiple paradigms in MMR and embraces the interactions and tensions arising from the use of such multiple paradigms (Tashakkori and Teddlie 2010). On the other hand, transformative-emancipation paradigm serves as the basis for MMR on social justice and inequality (Mertens 2007). The last two paradigms, critical realism and pragmatism are somewhat similar in that they both respond to the polarisation between positivism and

constructivism (Shannon-Baker 2016). However, Shannon-Baker (2016) explains that while pragmatism focuses on practical solutions and applicable for intervention studies, critical realism focuses on dialogues and predominantly applicable to evaluation-based studies. Pragmatism is also the most common paradigm for MMR (Johnson, Onwuegbuzie and Turner 2007). As is the case with other research concepts, pragmatism is ambiguous, however, it offers a "philosophy that attempt to fit together the insights provided by qualitative and quantitative research into a workable solution" (Johnson and Onwuegbuzie 2004, p. 16). That is, Pragmatism offers a middle ground between philosophical standpoints, as such does not embrace traditional dualisms. It places equal importance on experiments involving the physical world as well as social interactions and processes. Pragmatic philosophy also enables flexibility in data collection method which can draw on positivism/post-positivism (for quantitative research) or social constructivism (for qualitative research) as required by the research questions (Creswell and Creswell 2018). As a result of its flexibility, pragmatism enables a researcher combine methods and techniques appropriate for the research. This is important as quantitative and qualitative approaches have different ontological and epistemological paradigms. Therefore, pragmatism accepts that "there are singular and multiple realities that are open to empirical inquiry and orients itself toward solving practical problems" (Feilzer 2010, p. 8). Thus, while there may be multiple and constructed realities on a phenomenon, pragmatism also recognises that the same phenomenon can also be perceived as a single reality, thereby believing in a world that is constructed through objective and subject standpoints.

Several authors (Creswell and Creswell 2018; Johnson and Onwuegbuzie 2004; Nastasi, Hitchcock and Brown 2010; Shannon-Baker 2016) have pointed out that pragmatism is the most common paradigm and appropriate for MMR because of its pluralistic stance and emphasis on the practicalities, contextual appropriateness and potential outcomes of the research. Furthermore, Creswell and Creswell (2018) establish that this paradigm is concerned with applied research and focuses on identifying solutions to problems. In other words, pragmatism focus on the utility of the research findings (Feilzer 2010). Feilzer (2010) posit that the concept of utility in pragmatic research relates to reflexivity in research

practice, thus, making it useful for implementation or intervention-based studies. Therefore, pragmatism appropriately suits the MMR approach for this study for the following reasons:

1. As an outcome-oriented paradigm which focuses on practical implications of research, pragmatism is applicable because my study seeks to provide practical solutions to a real-world problem (challenges to early breast cancer detection).
2. The flexibility and pluralism of the pragmatic approach enabled me to integrate the quantitative and qualitative aspects in such a way that answers my research questions.
3. Lastly, there is dearth of research on studies which have reported the use of pragmatism as a stance to guide research on breast cancer, this makes an original methodological contribution to MMR.

3.2 The Study Site Description- Kajjansi Town Council

This study focused on Kajjansi town council, formerly Ssisa sub-county, located in Wakiso district in the central region of Uganda. Kajjansi town council was purposively selected for this study because previous research on the challenges to early detection of breast cancer had been conducted in the area (Ilaboya 2015; Ikhile, Gibson and Wahidin 2019). Secondly, the Kampala cancer registry which is one of the two cancer registries in the country draws data from Kyadondo county, which is located in Wakiso district (Wabinga et al. 2016). Wakiso district sits within the central region of Uganda and is engulfed within the capital city, Kampala. The district has a landmass area of 2,807.75km^2 and is bordered by Luweero and Nakaseke districts to the north, Kalangala district in Lake Victoria to the south, Mukono district to the east and Mpigi district to the west (Figure 3.3) (Wakiso District Local Government 2017). The most recent national population census estimated the district population to be around 2.7 million making it the most populous district with Kampala as the second, at approximately 1.6 million (Uganda Bureau of Statistics 2019). This high population size could be attributed to its proximity to the capital city, Kampala and increasing urban sprawl (Wakiso District Local Government 2017). The district's physical development plan also indicated that Wakiso has the highest number of women across the country (Wakiso District Local Government 2017). In terms of administrative units, Wakiso district has two counties,

Busiro and Kyadondo counties (Wakiso District Local Government 2018). The district also has 15 sub-counties, one municipality, 6 town councils, 148 parishes and 704 villages (Wakiso District Local Government 2018). The district has a peri-urban setting comprising of a mix of urban centres and rural settings (Wakiso District Local Government 2017) although Kajjansi town council is predominantly semi-rural. Prominent economic activities in the town council are similar across the district and include Agriculture, Fishing, Manufacturing, Sand Mining, Tourism, Commercial services and Informal businesses (Wakiso District Local Government 2017).

Figure 3.3: Map of Wakiso District (Wakiso District Local Government 2018)

Access to the study site was gained through my experience of conducting previous research in Kajjansi town council, and also supported by an existing institutional partnership between NTU School of Social Sciences and Makerere University School of Public Health (MakSPH) in Uganda (Musoke et al. 2016).

3.3 Data Collection and Analysis

Since I adopted a sequential explanatory MMR design, the data collection process is presented as two distinct phases: phase one and phase two.

3.3.1 Phase one: Quantitative data collection

Phase one comprised of the quantitative data collection which was conducted in 2017. To improve the PHC system for breast cancer service delivery, it is first important to assess the available infrastructure and breast cancer services provided to women in Kajjansi town council. Therefore, in line with the first objective of this study, I conducted a situation analysis during the quantitative phase to evaluate the existing PHC capacity for early detection of breast cancer in Kajjansi town council. Situation analysis is regarded as the first process in planning for health interventions and it involves the systematic assessment of a health issue to inform planning decisions (Schmets, Rajan and Kadandale 2016; WHO 2016b). Situation analysis forms the basis for a district health plan or district health report (Petersen et al. 2009), and is a broader term than health needs assessment as it not only captures the problems but also considers the strengths and assets of individuals, communities, and policies within a given setting or facility (WHO 2016b). Thus, it provides evidence to inform establishing or implementing health programmes. In addition to providing the basis for what programme should be put in place, it also provides guidance on what strategies are best suited for such programme (Schmets, Rajan and Kadandale 2016). Situation analysis is also important to provide context appropriate evidence to inform interventions (WHO 2016b). The use of situation analysis in health care research is well established as it has informed planning and implementation of various health programmes in SSA such as HIV (Treves-Kagan et al. 2017), mental health (Petersen et al. 2009) and cervical cancer (Chirenje et al. 2001). A situation analysis was necessary for this study because there is a dearth of research on the

availability or non-availability of breast cancer detection services provided at the PHC level in Kajjansi town council.

The situation analysis was conducted as two studies. Study one comprised of the PHC centres assessment while study two was an assessment with CHWs in the project area.

3.3.1.1 Health Centre Assessment (HCA)

I carried out an assessment of the existing government health centres in the study area in February 2017 using a researcher administered questionnaire. The HCA questionnaire was based on an existing and publicly available standardised tool, the Fred Hutchinson Breast Cancer Initiative (BCI) 2.5 Breast Health Care Assessment Questionnaire (Breast Cancer Initiative 2. 5 2017). This questionnaire was designed by the Breast Health Global Initiative to assess the overall capacity of health facilities in LICs for breast cancer control. Although the original questionnaire covered the whole breast cancer control continuum, that is, from early detection to survivorship. For this study I adapted it to focus on early detection spectrum and general health centre capacity questions. After modification, the original 32-page questionnaire was reduced to 12 pages (see Appendix 3.1).

Another modification I made was to add sections around other health services provided by the health centres and strengths and weaknesses of the health centres in relation to breast cancer detection. This decision aligned with the WHO's (2016b) recommendation that a situation analysis should not only capture the problem but also cover the strengths of the setting under assessment. I selected the BCI 2.5 tool not only for its appropriateness to assess breast health capacity but also because the validity of the tool had been demonstrated in the SSA context. For instance, it was recently used to assess breast health care in an East African country, Tanzania (The United Republic of Tanzania, Susan G Komen and Breast Cancer Initiative 2. 5 2017). Also, the BCI 2.5 tool distinguished between early detection and early diagnosis which was crucial for my study. Since the tool used had been externally validated, there was no requirement for a pilot study to pre-test the tool. However, the adapted questionnaire was reviewed by my Uganda based supervisor to ensure its cultural and language appropriateness for the Ugandan context. The modified HCA questionnaire used for the data collection had the following components:

1. Health centre overview
2. Early detection services for breast cancer
3. Patient data, records and tracking
4. Funding
5. Health promotion activities
6. Referral pathway
7. Human resources
8. Other health services
9. Strengths and weaknesses of the health facility in relation to early detection of breast cancer

Sampling Method

Purposive sampling was employed to include all the available government health centres in Kajjansi town council. Purposive sampling which is a type of non-probability sampling method was appropriate for the HCA as it enabled me to select a representative sample based on predefined criteria (Lavrakas 2008). As the focus of my study was on PHC delivery, my target sample was on health centres which provide health services at PHC level. Although there are a number of public (government) and private health centres in Kajjansi town council, the private ones were excluded because they are used by the minority of the community due to the associated out of pocket costs. Hence, only government health centres in the town council were targeted. The total number of government health centres in the town council is three, which were the focus of this study. Participant recruitment was done by approaching the health centre manager/person in charge. After explaining the purpose of the study, the manager then identified the most appropriate personnel to participate in the survey or participated themselves.

Data Analysis

Data analysis for the HCA was conducted through descriptive analysis. Descriptive analysis is a univariate form of analysis which is central to most quantitative data analysis and it involves summarising data sets using frequency, tables, charts and figures (Taylor 2005; Trochim 2020). Descriptive analysis was appropriate for this study since the objective of the HCA was

to map health service delivery capacity available for early detection of breast cancer. Descriptive analysis of the HCA data was conducted using Microsoft Excel 2016. Data was entered into Excel, checked to ensure quality, collated and presented using charts and tables.

3.3.1.2 Community Health Workers (CHWs) assessment

I also conducted an assessment among the CHWs in the study area because they play a crucial role in PHC delivery as established in the literature review (section 2.4.1). The assessment with the CHWs was conducted between July to August 2017 through the use of researcher administered questionnaires. The questionnaire was self- designed and semi-structured to contain both closed-ended and open-ended questions. Prior to data collection, I piloted the questionnaire among CHWs (separate to those who participated in the actual survey) in Uganda to ensure the questions could easily be understood and appropriate for the Ugandan context. The piloting was conducted in March 2017 after which the questionnaire was modified to include questions around whether male CHWs are able to offer breast care related services. Although the plan was to conduct the data collection in April/May 2017, but this was not possible due to weather conditions as it was rainy season in Uganda. Hence the data collection was delayed until July. The project area is a semi-rural area; when it rains, it becomes less accessible and difficult to get around. In view of this, it is important to note that weather conditions could affect data collection.

This questionnaire was then validated after review and approval by my supervisor in Uganda, after which it was translated to *Luganda* (see Appendix 3.2). Components of the questionnaire included:

1. Demographic information: parish, village and sex
2. Roles of CHWs
3. Health issues addressed
4. Incentives received by CHWs
5. Specific health services delivered to women
6. Breast cancer detection services
7. Health promotion activities

8. Perceptions of CHWs on strengths and weaknesses in relation to the PHC capacity to provide breast cancer detection

Although the official language in Uganda is English, the community members of Kajjansi town council communicate mostly in *Luganda*, their local language. Therefore, the questionnaire was translated to *Luganda* to make the data collection process more efficient. As a result of this, there was a requirement for in-country research assistance to support the administration of the questionnaire in the local language. The use of research assistants is not unusual and considered practical, especially for research in international settings where language and cultural differences can be a barrier to data collection (Stevano and Deane 2017). For instance, Teye (2008) who was registered as a doctoral student at the University of Leeds (UK) employed the assistance of field researchers to support with data collection in Ghana. For this study, the data collection for the CHWs assessment was supported by three field research assistants in Uganda who are part of the NTU-MakSPH partnership project team. Although it was not initially discussed or agreed, I decided to reimburse the research assistants for supporting with the quantitative data collection, as a sign of appreciation for their time. Fortuitously, I received the 2017 Barbara Rosenblum Breast Cancer Dissertation from the Sociologists for Women in Society which enabled me to do so. All three research assistants were responsible for the actual data collection while only one of them was responsible for entering the data into a pre-designed data entry spreadsheet on Microsoft Excel. Although my initial plan was to complete the data entry myself, a research assistant was required to ensure a seamless process. Since the data was collected in *Luganda* and the data entry spreadsheet was in English, there was a need for the data to be translated first. Although the data entry database was developed in English, the research assistant translated the open-ended questions back to English during data entry. Hence, I designed a data entry sheet to guide the process (see Appendix 3.3). I held periodic debriefing with the research assistant entering the data to monitor the progress and ensure the data was being entered correctly.

Sampling method

Similar to sampling for the HCA, all the CHWs present in Kajjansi town council were purposively targeted to be involved in the study. The assessment of CHWs targeted 300

participants which was the total number of CHWs working within the project area (Musoke et al. 2016). However, the total number of CHWs available during the data collection, hence involved in the study was 292.

Data Quality Assurance

After the data collection, I carried out quality checks to ensure the data had been entered correctly. Although the data entry recorded 293, quality checks revealed 292 data were entered. Spellings and names of villages in the CHWs assessment were also checked against existing literature and verified by my Uganda based supervisor.

Data Analysis

IBM SPSS 23 was used for descriptive analysis such as frequencies and cross-tabulations. Cross tabulation was done to show statistical associations especially in relation to the sex-disaggregated analysis and also to capture the number of villages by parish. In addition, Microsoft Excel was used to create graphs and tables for illustrative representations of the data. The close-ended data was cleaned and checked for completeness in Excel before exporting to SPSS for analysis, while the open-ended data was analysed manually in Excel.

3.3.1.3 Quality in the quantitative phase

Four quality criteria have been associated with quantitative research in social sciences, these include validity, generalisability, replicability and reliability, but reliability and validity are the most common (Bryman, Becker and Sempik 2008; Heale and Twycross 2015). Heale and Twycross (2015) and Twycross and Shields (2004) suggest that reliability relates to the repeatability of the data collection tool. Therefore, it can be inferred that repeatability and replicability are similar. On the other hand, validity is a measure of accuracy in terms of research findings (Roberts and Priest 2006). Generally, validity is mostly associated with experimental and cause and effect studies (Trochim 2020). In relation to generalisability, quantitative research is typically considered generalisable in comparison to qualitative research because it is based on a predefined approach (Watkins and Gioia 2015). In this case, the use of a validated and globally standardised tool, the BCI 2.5 for the HCA contributed to the reliability and generalisability of findings from the HCA.

In order to improve the overall rigour of the situation analysis, I used Treves-Kagan et al. (2017) four-stage approach to conducting situation analysis as a guide to ensure that my study was conducted in a systematic manner.

1. Laying the foundation: here I clearly defined the objectives and scope of the situation analysis and discussed planned activities with my supervisory team.
2. Preparing for the fieldwork: I conducted desk review to identify past questionnaires used for breast cancer detection assessment and also to inform design of the CHWs assessment tool. The CHWs assessment tool was piloted and both questionnaires were validated through external review by my supervisory team. At this phase, I also applied for ethics consideration as recommended by Treves-Kagan et al. (2017).
3. Conducting the fieldwork: The data collection process was documented in detail for clarity and transparency.
4. Data analysis and reporting.

3.3.2 Phase two: Qualitative study

Building on findings from the quantitative phase, the second phase of this study comprised of the qualitative component which was conducted between 8th January and 17th July 2019. The key objective of the qualitative phase was to examine how the PHC capacity can be strengthened for early breast cancer detection. This involved gathering rich, context-appropriate evidence that will inform practical interventions to promote early detection of breast cancer at the PHC level. According to Hesse-Biber and Leavy (2006) qualitative research is used to "discover, explain, and generate ideas/theories about the phenomenon under investigation" (p. 49). In the case of this study, the qualitative study was used to explain findings from the quantitative study. It has also been used to generate evidence about how breast cancer detection challenges can be practically addressed. Thus, this qualitative phase did not only focus on stating what should be done but unpacking the qualities of these suggestions and how they might be achieved. Specifically, the focus of the qualitative data collection was on 'what' and 'how' which is consistent with qualitative research as it has been recognised as useful to answer the what and how questions (Creswell 2015; Sullivan 2012; Teti, Schatz and Liebenberg 2020). Therefore, for the qualitative phase, I adopted a solution-

oriented stance to generate ideas which would serve as evidence about how breast cancer detection can be practically promoted in Kajjansi town council. A solution-oriented stance was important to generate insights which are not only generic but provide a contextual and clear pathway for action. Thus, laying the groundwork for future intervention(s).

Qualitative research seeks to provide deep and rich textual accounts through various methods including interviews, focus group discussions, content analysis, documentary analysis and participant observation (Brannen and Halcomb 2009; Denzin and Lincoln 2017; Watkins and Gioia 2015). Of all these methods, interviews are the most widely used (Brannen and Halcomb 2009). Interviews are integral to qualitative research (Watkins and Gioia 2015) and are used in various disciplines as a common way of generating knowledge about human and societies (Brinkmann 2017). Interviews are also useful for overcoming both spatial and time distances as "the researcher can reach areas of reality that would otherwise remain inaccessible such as people's subjective experiences and attitudes" (Peräkylä and Ruusuvuori 2017, p. 669). Interviews are either structured, unstructured and semi-structured depending on the level of structure of the qualitative questions (Bell 2014; Brannen and Halcomb 2009; Brinkmann 2017). According to Brinkmann (2017), the distinction between the various types of interviews should be thought of as part of a continuum with semi-structured interviews as the most common type associated with qualitative research. A semi-structured interview method was adopted for this research and designed to be carried out in a conversational style (Smith, Brett and Sparkes 2016) guided by a set of open-ended questions and prompts. Since I adopted a semi-structured style, the interview guide was not followed strictly but acted more as a prompt. In most cases, the logical flow of the interviews was participant-led, and my role was to ensure the conversation was bounded within the scope of my study/the interview. Otherwise, the direction and flow of the interviews were dependent on the participants. This participant-led style has been identified by Creswell and Creswell (2018) as a strength of qualitative research. Each of the interview was unique in the sense that it drew on participants' knowledge, experiences and personal insights. Following the challenges identified from the situation analysis and existing literature, a semi-structured interview guide was designed as a solution-oriented tool to gather specific, context-appropriate and practical solutions to potentially address the identified challenges (Appendix 3.4). The

interview guide was informed by five broad themes from the quantitative findings to be explored with participants:

1. Practical solutions to address the challenges to early breast cancer detection
2. Provision of organised breast cancer detection services through strengthening the PHC capacity
3. Integration of early breast cancer detection with existing PHC services
4. Capacity building of CHWs to provide early breast cancer detection services
5. Approaches to engage women in breast cancer detection

The semi-structured interviews for this study were conducted via Skype. Although semi-structured interviews like other interviews are usually conducted via face-to-face interactions, contemporary interviews now bridge distance and accessibility barriers as they are increasingly conducted through online mediation (Madge 2010). It has been argued that online mediated interviews lack critical aspects of a face-to-face interview which Brinkmann (2017) describes as "…embodied presence, which enables interpersonal contact, context-sensitivity, and conversational flexibility to the fullest extent" (p. 578). In contrast to Brinkmann's (2017) position, the use of online technologies is increasingly mediating daily lives and cultural experiences (Markham 2017; Weller 2017), and have expanded across the globe as a result of globalisation and technological advancements (Srinivasan 2018; Weller 2017). Indeed, the world is now construed more as a global village and more connected through the rapid proliferation of the internet (Srinivasan 2018). Common examples of online qualitative data collection methods include email interviews, instant messaging and Skype (Deakin and Wakefield 2014; Weller 2015). Skype is a preferred method for conducting interviews remotely as it has the functionality to support visual interactions which address some of the criticisms over telephone interviews and asynchronous web platforms (Hanna 2012; Seitz 2016). This is particularly in cases were the video functionality of Skype is integrated and maximised in the interview process. This video functionality thus makes it a preferred option to telephone interviews as the body language and non-verbal cues of participants can still be observed.

I did not start out to use Skype interviews as my initial plan was based on face-to-face data collection. However, due to logistics and personal constraints, it was difficult to travel at the scheduled time. In order to meet up with my PhD timeline, Skype was explored and used as an alternative. The piloting for the semi-structured interviews was also conducted via Skype. The data collection guide was piloted with two Africans who both have extensive knowledge of PHC in an African country from a health care specialist and NGO perspective. Based on the pilot interviews, the data collection guide was revised for clarity. The following changes were specifically made:

- Question on 'how can the identified challenges be addressed?' was revised to 'what are the solutions to the identified challenges?' for simplicity.
- After piloting, I added a question on 'underlying challenge': the reason for this is to understand the priority of the respondents in terms of breast cancer detection challenges.

3.3.2.1 Skype interview process

The use of Skype in qualitative research is an emerging area of practice which provides an alternative to the traditional face to face interviews (Deakin and Wakefield 2014; Weller 2017). Skype has been used across different disciplines. For instance, Skype was used in a pedagogy research in Sweden involving young girls with chronic illness to explore its use for communication (Simeonsdotter Svensson et al. 2014). Skype was also used in a management research with SMEs in England (Hay-Gibson 2009). Redlich-Amirav and Higginbottom (2014) also used Skype to conduct their PhD study in fragile communities in Palestine and Israel. The reason for using Skype in academic research varies. For instance, Redlich-Amirav and Higginbottom (2014) use Skype due to political difficulties in accessing participants who were based in Palestine and Israel while the researcher was studying in Canada. However, Skype has also been conducted based on the respondents' preference as was the case in Adams-Hutcheson and Longhurst (2017). More so, existing studies have used Skype in combination with face-to-face data collection or other online platforms. Hanna (2012) interviewed 3 participants via Skype while combining with face to face and telephone interviews while Weller (2017) combined Skype with Facetime in a qualitative longitudinal study of 50 young

people in the UK. For Hanna's (2012) research, Skype was used to reach participants outside England where the researcher was based. It is therefore evident that Skype offers flexibility in terms of accessing study participants, especially within international settings.

In terms of flexibility, the use of Skype was both advantageous and disadvantageous. The key advantage of conducting Skype interview was being able to spend more time in the (virtual) field. The benefit of this was that I had sufficient time to collect data and reflect on the initial findings to inform my data collection approach. The sampling method section below describes my logic of data collection. On the other hand, having sufficient time made it difficult to close out on the interviews. The time boundary for data collection was too fluid and I found myself stretching the timeline in order to accommodate more participants. The data collection period lasted for 7 months (8th January to 17th July 2019). Engaging study participants in the field physically for this period would have been difficult in a face-to-face interview because of the costs associated with travel and in-country living expenses. Although establishing rapport has been highlighted as a shortcoming of Skype interviews (Seitz 2016) but my experience on this study shows that whilst establishing a rapport can be difficult, it is certainly not impossible. This difficulty can also be alleviated by previous physical interactions/engagements with the field/participants. It was not difficult to establish rapport in this case as the interviews were building on previous research conducted in the community. I began each interview by first referring to my MAPH data collection conducted in 2015 and the situation analysis conducted in 2017. By reminding participants of the previous studies, I was able to establish a smooth flow and the research was no longer foreign to them.

Despite its opportunities, the use of Skype interviews can be hampered by technical issues (Seitz 2016; Smith, Brett and Sparkes 2016; Sullivan 2012). The first and most obvious requirement for a Skype interview is access to an internet-enabled device (laptop, iPad or smartphone) for both the researcher and participants. Due to the fact that the research was conducted in a semi-rural area, access to an internet-enabled device was limited. Therefore, this necessitated the need for a gatekeeper who supported with the interviews and was trained by my Uganda based supervisor on how to launch and use Skype on a laptop. The gatekeeper was one of the field assistants that supported with the quantitative data collection and he supported by taking the laptop to the respondent ahead of the agreed time

for me to then Skype in. In some cases, the interviews were held at the NTU-MakSPH field office based in Kajjansi town council. I also conducted two trial Skype calls with him prior to the interviews to test the Skype connectivity ahead of the interviews. Access to the internet network is one thing but having a reliable network connection is the crux to successfully conduct Skype interviews. In this case, deliberate efforts were made to go for the most reliable network connection, however, I experienced connectivity issues at some points, especially due to rainy weather conditions. A previous study has shown that rainy weather conditions can have adverse impacts on mobile and internet connectivity (Simeonsdotter Svensson et al. 2014). Another important factor in the use of Skype is in relation to cost. Although Skype interview is certainly cheaper than travelling to conduct face to face interviews, it is not free, hence described as being cost-effective (Lo Iacono, Symonds and Brown 2016; Sullivan 2012). From my end, I was not incurring additional costs as I had monthly access to unlimited internet from my network provider. However, there were costs associated with purchasing a strong internet on the laptop and providing transport refund for participants who had come to the field office to participate in the interview.

Sampling Method

For the qualitative data collection, I used a stratified sampling method whereby participants were divided into different categories (Robinson 2014). Specifically, I selected participants to represent five different categories: CHWs, PHC centres, district health team, Ministry of Health and NGOs. Separate qualitative question guides were designed for each category (Appendix 3.4). These five categories were targeted based on their involvement in PHC service delivery, as revealed through the literature review and situation analysis. The participants were recruited through various means including from established networks, use of an in-country gatekeeper, and through snowballing. For the CHWs category, I purposively selected participants who were fluent or had a good understanding of the English Language. This was essential to mitigate the need for a translator which might have been used in a face-to-face interview but difficult with an online interview. The other criteria for selecting the CHWs was equal representation of male and female CHWs. I purposively selected an equal number of male and female CHWs to get both views around gender norms and breast cancer detection. However, there is a possibility that purposive selection of CHWs who could converse in English

might have introduced a bias into the study. The selection of CHWs was done through the help of the gatekeeper. Prior to the interviews, I had discussed with the gatekeeper the criteria of participants which were the ability to converse in English and an equal number of male and female. Based on these predefined criteria, the gatekeeper and my supervisor in Uganda then supported with the recruitment of the CHWs participants. I initially planned to conduct ten interviews with CHWs but continued until I achieved data saturation, hence, the total number of CHWs interviews conducted was fourteen. Allowing my sample size to be determined by data saturation is good practice in qualitative research as it enabled me to keep generating new insights until there was no longer any new information from the CHWs (Fusch and Ness 2015).

In the case of the PHC centre category, I targeted the key health personnel who participated in the situation analysis across the three health centres. Only the participant from health centre II who participated in the situation analysis was available for the qualitative data collection, so, other health personnel who were knowledgeable about the health centre operations were purposively selected for health centres III and IV. For the district health team category, I recruited two representatives from the team responsible for health education and health promotion. These participants were identified through my existing networks and I contacted and recruited them directly. The Uganda Ministry of Health has non-communicable diseases and health promotion units which I used as a focal point for the interviews. The last category of participants is the NGOs participants who were more difficult to recruit than the others. The challenges faced with recruiting participants from this category was in multiple folds. First, there were no NGOs focusing on breast cancer or cancer or NCDs in the town council. Although two external NGOs (identified from the situation analysis) have conducted one-off breast cancer detection programmes, these were no longer in place at the time of the study. I made efforts to reach out to the two NGOs, but the efforts proved abortive. However, through my networks, I was able to access NGOs in Kampala whose focus was on NCDs generally.

At the start of the interview, I had no defined logic for the data collection. Rather, the logic was informed inductively upon starting the CHWs interviews. I started out with the CHWs interviews because they were the easiest to reach and whilst my intention was to conduct

the interviews based on availability of participants, it became apparent after conducting four CHWs interviews that the CHWs interviews had to precede the other categories. This is because the CHWs made reference to some activities carried out at the health centres, like health talks and outreaches which I highlighted to include in the health centres interviews.

In total, twenty-five semi-structured interviews were conducted with fourteen CHWs, five NGOs representatives, three PHC centres representatives, two district health team representatives and one representative from the Ministry of Health (Table 3.2). Thirteen of these participants were female, and the remaining were male. Out of the NGOs interviews conducted, only one was a grassroot cancer organisation. Three were focused on NCDs or CHWs and had international affiliations with the United States of America. The last NGO was a community-based initiative empowering woman in the project area; the other four were located in the capital city, Kampala. The grassroot NGO was inspired by a cancer survivor who set up the organisation as a way of giving back to the community and creating awareness that cancer can be cured when detected at an early stage. Also, two of the NGOs key informants (Mary and Sharon) had previously worked at the Ministry of Health before their current positions at the NGOs, so they were able to share their insights both from a government and NGO perspective. The names of these NGOs are not included for confidentiality. Each interview was audio-recorded and lasted between thirty minutes to an hour and half. A breakdown of the qualitative study participants is provided in Table 3.2.

Table 3.2: Breakdown of participants involved in the qualitative study

S/N	Date	Name	Category	Sex
1	08/01/2019	Alice	CHW	Female
2	09/01/2019	Mike	CHW	Male
3	09/01/2019	Vincent	CHW	Male
4	09/01/2019	Bianca	CHW	Female
5	09/01/2019	Stanley	CHW	Male
6	09/01/2019	Anita	CHW	Female
7	10/01/2019	Evelyn	NGO 1 (Grassroot cancer organisation)	Female
8	11/01/2019	Constance	CHW	Female
9	11/01/2019	John	CHW	Male

10	11/01/2019	Beatrice	CHW	Female
11	11/01/2019	Steve	CHW	Male
12	22/1/2019	Ben	CHW	Male
13	22/01/2019	Kate	CHW	Female
14	22/01/2019	Alex	CHW	Male
15	22/01/2019	Lydia	CHW	Female
16	31/01/2019	Felix	HC III	Male
17	31/01/2019	Kelvin	HC II	Male
18	05/02/2019	Caroline	HC IV	Female
19	15/02/2019	Agnes	District health team	Female
20	15/02/2019	Mark	District health team	Male
21	3/06/2019	Caleb	NGO 2 (CHWs focused)	Male
23	10/07/2019	Mary	NGO 3 (CHWs focused)	Female
22	11/07/2019	Sharon	NGO 4 (NCDs focused)	Female
24	16/07/2019	Lilian	NGO 5 (Community-based initiative)	Female
25	17/07/2019	Edna	Ministry of Health	Male

Qualitative Data Analysis

Data analysis is central to qualitative research to emphasise meanings and interpretations of data (Flick 2014) but there is no single universal way of qualitative data analysis (Coffey and Atkinson 1996; Maguire and Delahunt 2017). DeCuir-Gunby, Marshall and McCulloch (2011) refer to qualitative analysis as a sense-making undertaking. Although the open-ended nature of qualitative methodology has been identified as one of its strengths, however, Castleberry and Nolen (2018) refer to this as a shortcoming because of the difficulty associated with analysing texts rather than numbers. That said, a key factor in qualitative research is that data collection and analysis can either be conducted simultaneously or analysis can be conducted after data collection. The qualitative research process is also iterative (Bazeley 2013). As Coffey and Atkinson (1996) point out, "the process of [data] analysis should not be seen as a distinct stage of research; rather, it is a reflexive activity that should inform data collection, writing, further data collection, and so forth" (p. 6). The data collection and analysis for this

study were done concurrently as recommended by Coffey and Atkinson (1996) such that the initial data strengthened the next data collection.

There are different ways of analysing qualitative data including thematic analysis, framework analysis, conversation analysis and narrative analysis (Denzin and Lincoln 2017; Watkins and Gioia 2015), but thematic analysis is the most common and is widely used in social sciences research (Boyatzis 1998; Braun, Clarke and Weate 2016; Castleberry and Nolen 2018). Braun and Clarke (2006) define thematic analysis as a qualitative analytical "method for identifying, analysing, and reporting patterns (themes) within data" (p. 79). In establishing the usefulness of thematic analysis, Braun and Clarke (2006) further state that thematic analysis is a foundational method that underpins other qualitative analysis methods. One of the contrasting features of thematic analysis to other analytical methods is that it identifies "patterns of meaning" (Braun, Clarke and Weate 2016, p. 151) and provides evidence to illustrate or interpret these patterns. Thematic analysis also offers a flexible yet structured approach (Nowell, et al. 2017) especially in terms of paradigmatic orientations (Braun, Clarke and Weate 2016) which makes it suitable for research with strong practical implications, such as this study. There are different models of thematic analysis, for example, Castleberry and Nolen (2018) present a model comprising of five steps and Guest, MacQueen and Namey (2011) present a model of applied thematic analysis. However, Braun and Clarke's (2006) non-linear 6-step procedure on how to conduct thematic analysis has been recognised as the most widely used framework in social sciences because of its clarity (Maguire and Delahunt 2017). The thematic analysis process provided by Braun and Clarke (2006) provides an iterative framework of actively engaging with the data set. The six steps used are described below:

- ***Step 1: Data Familiarisation***

Braun and Clarke (2006) and Bazeley (2013) describe this first phase of thematic analysis as immersing one's self into the data by transcribing interview recordings and then reading and re-reading the transcripts. Bazeley (2013) summarise the data familiarisation step as: read, reflect and connect. This step begins with transcription and deepens understanding of the data and begins the search for initial codes and patterns. In a published article on the use of

thematic analysis for pharmacy education, Castleberry and Nolen (2018) recommend self-transcription to foster closeness to the data. Although, they acknowledge that this process can be daunting and time-consuming, they infer that the closeness to the data outweighs this con. The process of transcription was a period of complete re-immersion into the field as it brought the participants voices back to life. I transcribed the data orthographically, that is, verbatim description (Smith and Sparkes 2016). This approach is not free of the researcher's judgement as I had to decide what level of details to include such as 'emmm' (for emphasis) or 'eh!' (for surprise). Although there is no right way of transcribing (Smith and Sparkes 2016), I chose to include these levels of details in order to draw emphasis on important expressions made by participants. I also took notes to highlight key points and possible areas of follow-up during the interview. These notes formed identification of preliminary codes as they were based on "first impression" (Saldaña 2015, p. 4). Within this step, I also developed a data management process to handle the interview transcripts whereby all transcripts were labelled with participant category acronyms and number of respondent e.g. CHW 8. An excel spreadsheet was created to keep records of participant attributes, date of interviews and comments.

- ***Step 2: Coding***

Castleberry and Nolen (2018) refer to coding as a process of disassembling the data to create meaningful categories. There is no universal approach for coding in qualitative research (Decuir-Gunby, Marshall and Mcculloch 2011) but coding enhances knowledge of the data (Bazeley and Jackson 2013) as it is the process of knowing the data (Decuir-Gunby, Marshall and Mcculloch 2011). Generation of codes can be theory-driven (priori) or data-driven (emergent or driven by research goals) (Castleberry and Nolen 2018; Decuir-Gunby, Marshall and Mcculloch 2011). Data-driven code generation is an inductive process which does not involve fitting the data into a predefined theory or framework as is the case with theory-driven coding (Braun and Clarke 2006). That said, researchers have identified that inductive analysis is not entirely free of preconceived theoretical positions due to researchers bias as every research is premeditated and often informed by a theoretical position (Bazeley 2013; Braun and Clarke 2006). Interpreting qualitative data analysis also begins with coding, as

coding itself is an interpretative exercise (Saldaña 2015) rather than just a data reduction exercise.

The coding for this study was data-driven and done in two cycles. This approach is consistent with Saldaña (2015) and Bazeley (2013) position that coding is typically done in two cycles. The first cycle of microanalysis is more exploratory and referred to as open coding, which Bazeley (2013) terms "opening up the data" (p. 161) while the second is more focused and analytical. Braun, Clarke and Weate (2016) also talk about coding in two stages as they recommended "going through the dataset twice when coding, to ensure a systematic, coherent and robust set of codes" (p. 198). Specifically, Braun, Clarke and Weate (2016) suggested that doing a second coding process might facilitate identification of more latent codes which draws out implicit meanings and interpretations.

The first cycle of coding was done manually using the comments function on Microsoft Word 2016 version (Appendix 3.5). Then a clean version of the transcript was exported to NVivo for a more focused and conceptual second cycle coding (Appendix 3.6). Although time-consuming, the manual coding fostered closeness to the data which is a shortcoming of NVivo (Bazeley and Jackson 2013). On NVivo, responses were coded with the questions to enable me to understand the context of the participants response better. According to Bazeley and Jackson (2013), this is important for "methodological and practical reasons" (p. 89). My decision to use NVivo was not only to aid the coding process but also to facilitate the conceptual and thematic visualisations. For instance, Bazeley and Jackson (2013) clarified that NVivo can be used for the management of data and ideas, data querying, data visualisation and reporting.

- ***Step 3: Generating themes***

Step three of the analysis focused on identifying and searching for themes through analysing the codes. Saldaña (2016) refers to this step as theming, that is, an "outcome of coding, categorisation, and analytic reflection" (p. 198). According to Braun, Clarke and Weate (2016), the analytic aspect of thematic analysis begins with this phase and runs through the fourth and fifth steps. Gender-based analysis was also conducted in this phase by assigning sex attributes to the codes.

- ***Step 4: Refining themes***

This step involved merging and breaking down the identified themes. The themes were categorised across three levels as suggested by Clarke and Braun (Clarke and Braun 2013): overarching themes, themes and sub-themes. In refining the themes, the memo function on NVivo was used to document changes made.

- ***Step 5: Defining the themes***

This step involved ascribing names to themes and defining them. In defining the themes, a short descriptive note was prepared for each theme identified on NVivo. This helped to capture the essence of the themes (Braun, Clarke and Weate 2016).

- ***Step 6: Writing***

Writing in qualitative research is described as the interpretative stage and is embedded within thematic analysis (Braun and Clarke 2006). At this data interpretative stage, Bazeley (2013) suggest three sequential steps to draw out analytical inferences: describe, compare and relate. However, Guest and Namey (2011) expatiated that interpretation is weaved across the thematic analysis process from identifying the codes to defining the themes. That means interpretation does not begin at the writing stage. Also, the writing phase includes data presentation where the data is supported with extracts from the transcripts and extends to the discussion (Braun and Clarke 2006) where the findings are discussed in relation to my research objectives and the existing literature. According to Braun, Clarke and Weate (2016), the data can be presented through illustrative, analytical or combined approaches. I used a combined approach which involved illustrative and analytical presentation of the data.

An illustration of my analysis process is provided in Figure 3.4 to show the iterative process taken to analyse the data.

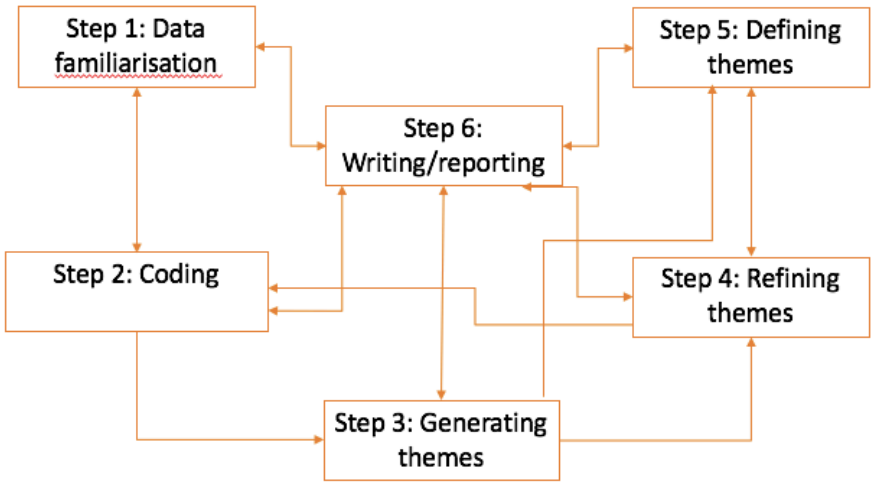

Figure 3.4: Thematic analysis process

3.3.2.2 Quality in the qualitative phase

The value of qualitative research lies in the rigour of the data collection and analysis processes and according to Morse, et al. (2002), "Without rigo[u]r, research is worthless, becomes fiction, and loses its utility" (p. 2). The definition of rigour according to Morse (2002) is based on reliability and validity which can be attained through verification and self-correcting strategies. Silverman (2016) defines this simply as credibility of inferences drawn from the data collected. However, Lincoln and Guba (1985) used trustworthiness as a parallel term for rigour. According to Nowell et al. (2017), trustworthiness is the clear documentation and disclosure of a systematic approach to data analysis and it is essential to determine the credibility of the qualitative data and findings. In other words, rigour in the qualitative research context can simply be understood as a process of quality assurance. The qualitative research process in this context refers to both data collection and analysis. In this section, I adopted Lincoln and Guba's (1985) four criteria for rigour (1. Credibility 2. Transferability 3. Dependability 4. Confirmability) as they are the most widely used in the social sciences (Korstjens and Moser 2018; Watkins and Gioia 2015).

Credibility relates to the accuracy of research findings and it is analogous to internal validity in quantitative research (Korstjens and Moser 2018; Schwandt, Lincoln and Guba 2007). One of the ways of assessing credibility is through prolonged engagement in the field (Korstjens

and Moser 2018). In this case, the use of Skype facilitated the process of prolonged engagement in the field and enabled the data to be collected in a logical manner such that findings from one category informed the others. Member check is another strategy for improving the credibility of qualitative research (Korstjens and Moser 2018). The process of sharing and discussing my research findings with my supervisory team also helped to build the credibility of the data analysis and interpretations. In contrast to quantitative research, qualitative research findings are not usually generalisable (Watkins and Gioia 2015) because most often than not, they are context specific and the characteristics of those contexts may not be replicable (Castleberry and Nolen 2018). Rather, a strength of qualitative research is transferability which relates to learning from study findings to inform similar situations (Schwandt, Lincoln and Guba 2007). Although the qualitative research did not elicit generalisable findings, the findings derived from this study can be adapted and transferred to fit similar contexts.

Confirmability is the qualitative version of objectivity in quantitative research (Watkins and Gioia 2015) and is similar to dependability as they both refer to the audit trail documentation during the qualitative research (Schwandt, Lincoln and Guba 2007). Therefore, both can be implied as an assessment of the transparency of the research process. Specifically, Anney (2014) states that confirmability can be achieved through reflexivity, triangulation and audit trail while dependability can be determined through coding strategy, triangulation and member checking. That means member checking is a determinant of credibility and dependability as it has been highlighted and also discussed in relation to credibility. The dependability was enhanced through the two-cycle coding I employed which enabled me to verify as well as ensure that my interpretations are grounded in the data set. Furthermore, it can be argued that the use of NVivo contributed to the dependability as it is widely believed that qualitative data analysis software help to ensure rigour during the qualitative analysis process (Bazeley and Jackson 2013). Lastly, the confirmability of my research process for this study is discussed through a reflexive account. A reflexive account is being provided within this criterion to provide an audit trail. The reflexive account does not only cover the qualitative research but the whole MMR process. Reflexivity is key as it describes my inputs and influence as a research instrument (Maguire and Delahunt 2017; Nowell et al. 2017).

Reflexivity has been embedded into the data collection through the integration of reflexive accounts where applicable. Additional reflexive account of my overall PhD process is provided as a stand-alone section at the end of this thesis. For this section, I focus my reflexive account on my positionality and limitations faced during the research process.

Researcher's positionality

Positionality is a core aspect of reflexivity as it captures how the researcher's personal characteristics influence and are influenced by the research process (Berger 2015; Teye 2012). Similar to Teye (2012), I took on different positions during the quantitative and qualitative processes. This section describes my positionality in relation to my identity as a young black African woman from Nigeria conducting research on women in another African country (Uganda). In particular, I focus on my visibility, that is in terms of how my presence was felt in the field at different points of the research. During the HCA, my role could be likened to that of a typical researcher who goes into the field, conducts research and immediately leaves the field. At this point, I took a direct but objective, outsider stance with minimal engagement with the field. In the case of the CHWs assessment, my visibility was obscured as my presence in the field was indirect and reflected through the research assistants who were collecting the data. However, my position shifted during the qualitative research where I was both an outsider and an insider. As an insider, I was a black African with the same skin colour as my study participants and with whom I have been engaging with in the field of breast cancer research in Kajjansi town council since 2015. Yet, I was an outsider as I was trying to learn and understand through the eyes of my study participants. These different positions did not only determine how I interact with my study participants but also how they perceived me. Even though I was [in]visible to the study participants during the CHWs assessment, I owned the research and then 'revealed' myself to them by reminding them of the survey which made them relax and open up to me during the qualitative data collection thus providing insider access to me.

Study limitations

The key limitation was time constraint in relation to the qualitative data collection. Since the study was conducted in two phases, I could not collect all the data at once during my first

field visit in March 2017 and I had planned to return the following year in February 2018 but by then I was pregnant and was advised not to travel. After that, getting the time to travel became difficult but I was able to switch from face to face to Skype interviews. Also, during the qualitative interviews, I observed that the participants naturally tended towards explaining the problem rather than suggesting solutions. It took deep probing and gentle steering to get them to focus on the solutions rather than the problems. A possible reason could be because the problem is a current reality which they can easily share whereas asking for an ideal solution, 'what could' be rather than 'what is' requires more thinking and reflection.

The major challenge experienced during the quantitative data collection was the inability to follow up during the CHWs assessment. While a qualitative design would have enabled immediate follow-up on responses, it was unable to do this with the quantitative questions which were predominantly closed-ended. This was also affected by the fact that data collection was done by research assistants. Although not extensively covered in existing literature, Stevano and Deane (2017) suggests that there is no way the use of research assistants will not affect the data collection process. Hence, there is a need to be explicit as possible when designing a questionnaire especially in cases where data collection is supported by research assistants.

3.4 Ethics Considerations

Ethics is defined as "a coherent and consistent system of morality, values, virtues, and responsibilities that guide [the research process]" (Griffiths, Martin and Sinclair 2013, p. 12). Ethics approval was required primarily because the study involved collecting and analysing primary data about and from human participants. Ethics approval was obtained from the NTU College of Business, Law and Social Sciences Research Ethics Committee. The ethics approval was also obtained in phases as the data collection was sequential and comprised of two distinct phases. To ensure compliance with the British Sociological Association which was the ethical code of practice guiding this study, all ethical considerations such as informed consent, confidentiality and anonymity, data storage and management were adhered to at every stage

of this research. The British Sociological Association digital research guideline was also adhered to for the qualitative phase of this study as Skype was used for data collection.

Informed consent

The study participants were fully informed about the purpose of the study and what their participation will entail before they were asked to provide their consents. For the HCA, written consents were obtained from all three participants. For the CHWs assessment, the consent forms were developed in English but explained to the CHWs in Luganda before obtaining their consent which was either given through writing or verbally (see Appendix 3.7 for participants' information sheet and consent form used during the quantitative data collection). Informed consent during the Skype interviews was not so straight forward as there was no face-to-face interaction for participants to provide written consents. Hence, verbal consent or written consent via email which is acceptable for Skype interviews (Madge 2010, Sullivan 2012) was used. However, to ensure that all verbal consents were appropriately recorded, consent was explicitly obtained from each participant as follows:

> *…but before we proceed, I would like to get your consent that you are happy to be part of this interview.*

See Appendix 3.8 for the participants' information sheet used during the qualitative data collection.

Confidentiality and anonymity of research data

In terms of confidentiality and anonymity, there was a possibility that the study participants could be directly or indirectly identified in the outputs from this project, especially for the HCA and qualitative research participants. Therefore, in compliance with the British Sociological Association ethical guidelines, the confidentiality and anonymity of participants were respected by ensuring that sensitive details such as participants' names, institution details or contact details are not collected or recorded during data collection. Any information that gives any clue to the participant's identity, was removed from the questionnaire. To maintain anonymity, a unique identifier (numbers) was used during the CHWs assessment to identify respondents. Although the use of identifiers for the CHWs assessment ensured

anonymity, it was however difficult to follow-up on respondents. While it is important to protect the identity of respondents, researchers should also bear in mind the need to keep a personal and confidential log of respondents for easy follow-up. A confidential log was used during the qualitative data collection. Pseudonyms were also used during the qualitative data analysis rather than codes or numeric identifiers in order to maintain the human characteristics of the participants.

Privacy

Privacy during the research was ensured by collecting the data in private spaces. For the HCA, data collection was conducted in an office while data was collected from CHWs at their houses through a door-to-door approach. During the interviews, the CHWs were invited to the NTU-MakSPH field office where the interviews were held. Although a gatekeeper supported with the Skype process, after setting up, he would leave the room and shut the door leaving only the participant in the room.

Data storage and management and archiving

Data collected was accessible only to the research team (researcher and supervisors). All data were stored as encrypted files on a private laptop and NTU One-drive cloud storage for back up.

Risk assessment

The overall risk associated with the study was minimal. In terms of participants, the main risk identified was that unpublished information about the participants or participants' organisation may be collected. However, participants' confidentiality and anonymity were respected to mitigate this risk. To mitigate risks on the field, an international risk assessment was completed prior to the field data collection in order to ensure my safety abroad during the quantitative data collection.

Chapter Summary

This chapter describes the use of a sequential explanatory mixed methodology design for this study. The methodology comprised of quantitative and qualitative data collection conducted

in sequence. The quantitative data collection was conducted first to evaluate the availability of early detection services for breast cancer in Kajjansi council from the perspectives of the PHC delivery system through health centre and community health worker assessments. This was then followed by the qualitative data collection which used semi-structured interviews to examine how the PHC capacity can be strengthened to deliver early breast cancer detection services for women. The qualitative data was collected from CHWs and key informants representing NGOs, health centres, district health team and the Ministry of Health. The next chapter presents and discusses the findings from the quantitative phase of this study.

CHAPTER FOUR

4.0 SITUATION ANALYSIS FINDINGS

This chapter presents and discusses findings from the first phase of data collection: the situation analysis. The objective of the situation analysis was to evaluate the existing PHC capacity to deliver early breast cancer detection services for women in Kajjansi town council. The situation analysis was quantitative in nature and comprised of two studies:

- Study 1: Health Centre Assessment of the existing government health centres (n=3); and
- Study 2: Assessment of community health workers within the project area (n=292).

Specifically, the situation analysis was conducted to present findings on the:

- overview of the government funded PHC delivery system in Kajjansi town council;
- availability of early detection services for breast cancer at the PHC centres within the town council; and
- challenges around early detection of breast cancer from a PHC perspective.

In addition to presenting these findings, this chapter discusses the findings in relation to existing literature and draws out implications which informed the qualitative phase of this study.

4.1 Primary Health Care Delivery System in Kajjansi Town Council

Findings from the situation analysis showed that three government funded Health Centres (HC) exist within the town council, and all three operate at a PHC level. The health centres were: Nsaggu HC II, Nakawuka HC III and Kajjansi HC IV. These three health centres and Community Health Workers (CHWs) make up the PHC system in Kajjansi town council (Figure 4:1).

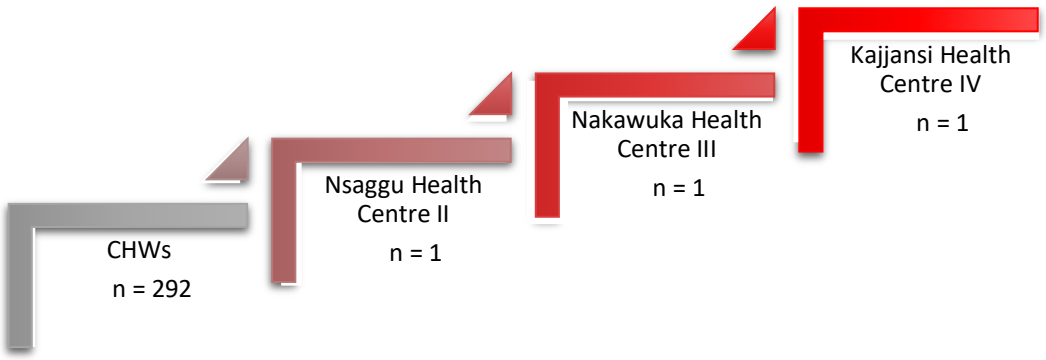

Figure 4.1: Primary health care system in Kajjansi town council

The step-up figure above (Figure 4.1) shows the different levels occupied by the three health centres and CHWs within the PHC system in Kajjansi town council. The respondents indicated that health services at these levels are provided free, at no cost to the individual.

4.1.1 Overview of the primary health care system in Kajjansi town council

Sixty-two villages and eleven parishes were identified as the entities that make up the town council. The three health centres and CHWs were distributed across the sixty-two villages within eleven parishes in the town council (see Appendix 4.1 for a full list of parishes and villages). Nsaggu HC II, Nakawuka HC III and Kajjansi HC IV are situated in Nsaggu, Nakawuka and Kitende parishes respectively (Figure 4.2).

All the CHWs (n=292) from all sixty-two villages in Kajjansi town council participated in the survey. The situation analysis revealed that majority (78.8%; n=230) of the CHWs surveyed were female.

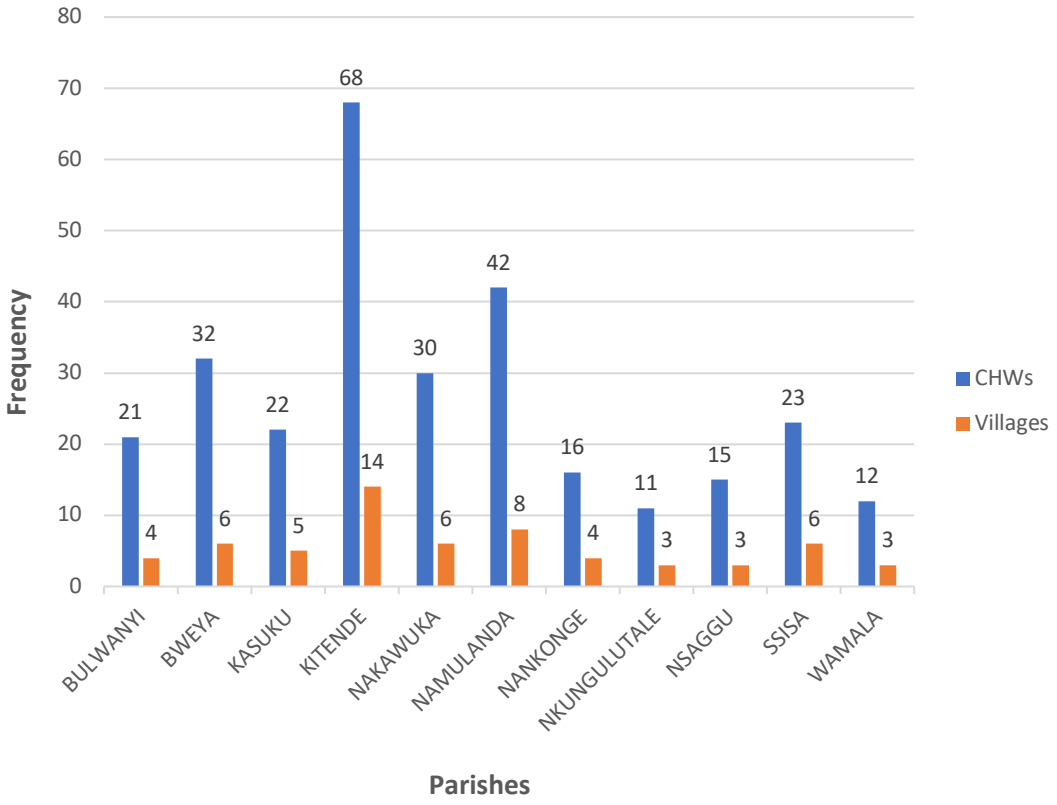

Figure 4.2: Number of villages and CHWs respondents by Parish

It can be seen from the Figure 4.2 that Kitende parish, where the HC IV is located, had the biggest size in terms of the number of villages (n=14), and also had the highest number of CHWs (n=68; 23.3%). Nakawuka which had the HC III was significantly smaller in size compared to Kitende with six villages, with less than half the number of villages for Kitende parish. The number of CHWs in Nakawuka was also significantly lesser (n=30; 10.3%) than that of Kitende parish. Nsaggu, which had the HC II, was one of the parishes with the lowest number of villages (n=3). The number of CHWs in Nsaggu parish (n=15; 5.1%) was half of those in Nakawuka parish.

4.1.1.1 Overview of the primary health care centres

Available Infrastructure

Nsaggu HC II was the smallest of all the three health centres within the project area, with only one examination bed, and attended to outpatients only. The HC II had no source of electricity and relied on piped water as its only source of water. The health centre also lacked essential

necessities such as alcohol hand rub, paper towels, hand dryers, single-use syringes and medical masks. However, the survey established that the health centre had disinfectant, gloves and medical gowns for staff use.

Nakawuka HC III had a bigger capacity than Nsaggu HC II with six beds. Nakawuka HC III also had access to electricity supply from the national power grid, although it relied on lamps as back up during periods of power outages. Water for use within the health facility was obtained through borehole and piped water. Similar to HC II, the HC III also lacked alcohol hand rub, paper towels, hand dryers and medical masks, but provided disinfectant, single-use syringes, gloves and medical gowns for staff use.

Kajjansi HC IV was the most equipped in terms of infrastructure. The HC IV had twelve beds, two water sources – piped water and rainwater harvesting, and electricity supply was through the district power grid while candles and lamps were used as a back-up. The HC IV relied on piped water and rainwater harvesting as the source of water for staff and patient use. Like the other two health centres, HC IV lacked paper towels and hand dryers but provided disinfectant, alcohol hand rub, single-use syringes, gloves, medical masks and gowns.

Table 4.1: Summary of infrastructure available at the three health centres

Infrastructure	HC II	HC III	HC IV
Bed	1	6	12
Electricity	x	Power grid, lamp	Power grid, lamp, candles
Water	Piped water	Borehole, piped water	Piped water, rainwater harvesting
Disinfectant	✓	✓	✓
Alcohol hand rub	x	x	✓
Paper towels/hand dryers	x	x	x
Single-use syringes	x	✓	✓
Gloves	✓	✓	✓
Medical masks	x	x	✓
Medical gown	✓	✓	✓

Human Resources

The situation analysis further revealed that the human resources at each of the health centre were proportionate to its capacity (Table 4.2). Nsaggu HC II had the least human resource capacity with a total number of five staff. Nakawuka HC III had a bigger capacity than the HC II with more number and diversity of staff (n=12). Kajjansi HC IV had the highest human resources capacity (n=36). The human resources in the health centres comprised of clinical officers, nurses, midwives, pharmacists and allied health workers. All the health centres were staffed with at least one clinical officer and nurses but there were no midwives in Nsaggu HC II.

Table 4.2: Human resources capacity of the three health centres

Human resources	HC II	HC III	HC IV
Clinical officers	1	2	2
Nurses	2	4	15
Midwives	0	2	5
Allied health workers	2 nursing assistants	● 2 laboratory technicians ● 2 health assistants	● 3 nursing assistants ● 4 health assistants ● 1 laboratory technician ● 1 laboratory assistant ● 1 health educator ● 1 vector control assistant ● 1 dental assistant ● 1 counsellor ● 1 Pharmacist
Total	5	12	36

Medical Records and Tracking

Although Nakawuka HC III and Kajjansi HC IV indicated that they had paper-based medical records department with one staff each, all the three health centres assessed lacked a recording system for breast cancer cases. Kajjansi HC IV added that the medical records department collated daily and monthly patient records and was in the process of migrating to an electronic patient records system which had just been introduced at the time of the

study. In addition, the HC IV estimated that about ten women attend the health centre monthly for breast health concerns but could not provide an estimate of women who had symptoms of breast cancer, or women with suspicious findings who did not return after their initial consultation.

4.1.1.2 Roles of CHWs in relation to primary health care delivery

From the situation analysis, the CHWs referred to themselves as health centre I, and intermediary between community members and the health centres. The CHWs added that they report health issues to the health centres, and support with immunisation and distribution of essential medicines. Additionally, the CHWs passed health information from the health centres to community members and reported being involved in household census exercise. The CHWs further indicated that their roles broadly span across health promotion and education about child health, adolescent health, maternal health, care for elderly, sanitation and hygiene. CHWs were asked to describe their roles in their own words, which have been categorised and detailed in Figure 4.3.

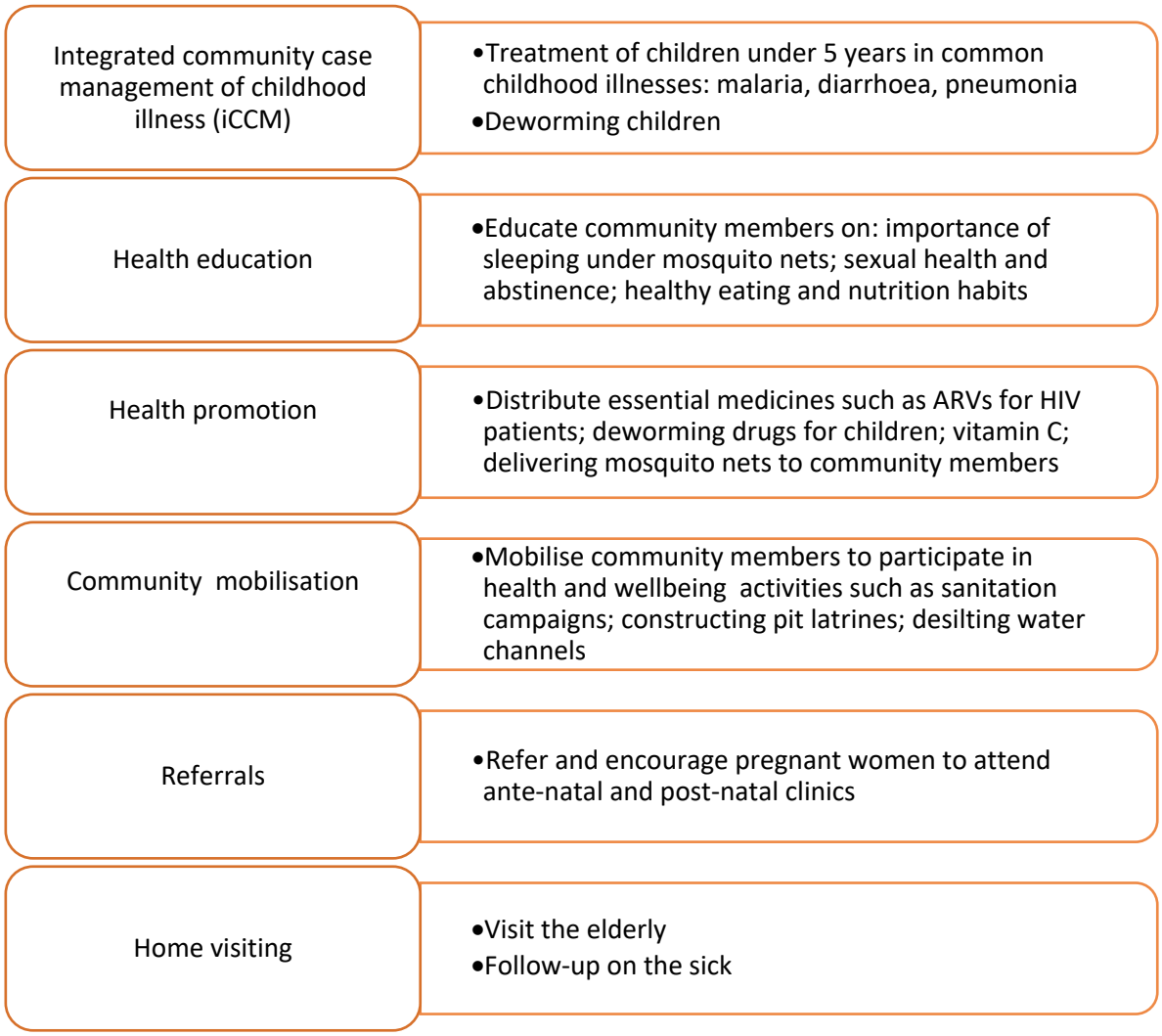

Figure 4.3: Roles of CHWs in Kajjansi town council

These roles are further disaggregated by sex of the CHWs as presented in Table 4.3.

Table 4.3: Breakdown of the CHWs roles by sex

Roles of CHWs	Total CHWs		Female CHWs		Male CHWs	
	Frequency (n=292)	Percentage (%)	(n=230)	Percentage (%)	(n=62)	Percentage (%)
iCCM	113	38.7	94	40.9	19	30.6
Health promotion	31	10.6	25	10.9	6	9.7
Health education	209	71.6	163	70.9	46	74.2
Community mobilisation	58	19.7	47	20.4	11	17.7
Home visiting	58	19.7	42	18.3	16	25.8
Referral	14	4.8	13	5.7	1	1.6

Majority of the CHWs, both female and male, were involved in health education. Only a few CHWs (n=14; 4.8%) indicated referral as one of their roles.

The CHWs further established that the widely used platforms for carrying out their health promotion and education roles involved one on one interactions through household visits, community gatherings and consultation from community members. Table 4.4 below presents the different health promotion and education platforms and number of CHWs who utilise them.

Table 4.4: Health promotion and education platforms used by CHWs in their roles

Health promotion and education platforms	Total CHWs		Female CHWs		Male CHWs	
	Frequency (n=292)	Percentage (%)	Frequency (n=230)	Percentage (%)	Frequency (n=62)	Percentage (%)
Household visits	291	99.7	230	100.0	61	98.4
Community gatherings	253	86.6	198	86.1	55	88.7
Consultation from community members	284	97.3	222	96.5	62	100.0
Leaflets	14	4.8	12	5.2	2	3.2
Posters	38	13	28	12.2	10	16.1
Television	1	0.3	0	0.0	1	1.6
Others	16	5.5	11	4.8	5	8.1

Other health promotion platforms indicated by the CHWs include churches, during treatment of children and immunisation, at health facilities, invitation to community events, and through savings and credit cooperative associations.

Incentives for CHWs

The situation analysis established that the CHWs are supported to carry out their roles through the provision of financial and non-financial incentives. The percentage of CHWs who indicated they had received non-financial incentives was greater (n=290; 99.3%) than those who had received financial incentives (n=277; 94.9%) from non-governmental project

initiatives. Non-financial incentives identified include gumboots, umbrellas, t-shirts and solar equipment.

4.1.2 Health issues addressed at the primary health care level in Kajjansi town council

Health services provision at the PHC level focused predominantly on communicable diseases including malaria, HIV/AIDs, pneumonia, diarrhoea, maternal and child health, family planning and sexual health services (Table 4.5).

Table 4.5: Health services provided at the health centres

Health issues addressed at the health facilities	HC II	HC III	HC IV
Malaria	✓	✓	✓
HIV/AIDs	✓	✓	✓
Tuberculosis	x	✓	✓
Pneumonia	✓	✓	✓
Diarrhoea	✓	✓	✓
Maternal and child health	Partly	✓	✓
Family planning services	✓	✓	✓
Sexual health	✓	✓	✓
NCDs	x	✓	✓
Basic diagnostic services	x	✓	✓
Other	x	✓	✓

Nsaggu HC II indicated that basic maternal and child services are provided at the health centre while others are referred to the HC III or IV. The NCDs addressed at Nakawuka HC III and Kajjansi HC IV were diabetes and hypertension. In addition, Nakawuka HC III provided eye services while Kajjansi HC IV provided services relating to mental health and safe male circumcision. None of the health centres indicated cancer as a health issue addressed.

Similarly, CHWs focused on communicable diseases as shown in Table 4.6. Only a few CHWs from Bulwanyi parish (n=5; 1.7%) indicated that they provided health services relating to cancer. Three of the five CHWs who reported addressing cancer were male.

Table 4.6: Health services provided by the CHWs

Health issues addressed by CHWs	Total CHWs		Female CHWs		Male CHWs	
	Frequency (n=292)	Percentage (%)	Frequency (n=230)	Percentage (%)	Frequency (n=62)	Percentage (%)
Malaria	292	100	230	100.0	62	100.0
HIV/AIDs	291	99.7	230	100.0	61	98.4
Tuberculosis	272	93.2	213	92.6	59	95.2
Pneumonia	291	99.7	230	100.0	61	98.4
Diarrhoea	292	100	230	100.0	62	100.0
Maternal and child health	288	98.6	228	99.1	60	96.8
Family planning services	244	83.6	195	84.8	49	79.0
Sexual health	268	91.8	212	92.2	56	90.3
Cancer m	5	1.7	2	0.9	3	4.8
Other NCDs	1	0.3	1	0.4	0	0.0
Others	79	27.1	65	28.3	14	22.6

Other services indicated include safe male circumcision, alcohol intake awareness, and children nutrition. One of the male CHW who indicated cancer specifically stated cervical cancer.

It is important to note that some of these health services provided at PHC level were specific to women such as maternal and family planning services. In relation to this, 94.5% (n=276) of CHWs responded that they provided health services specifically related to women's health (Figure 4.4). These services were related to maternal and child health care and include provision of antenatal and postnatal support by encouraging women to attend health centres; providing advice to women on how to maintain proper hygiene during and after pregnancy; encouraging breastfeeding; and offering family planning advice.

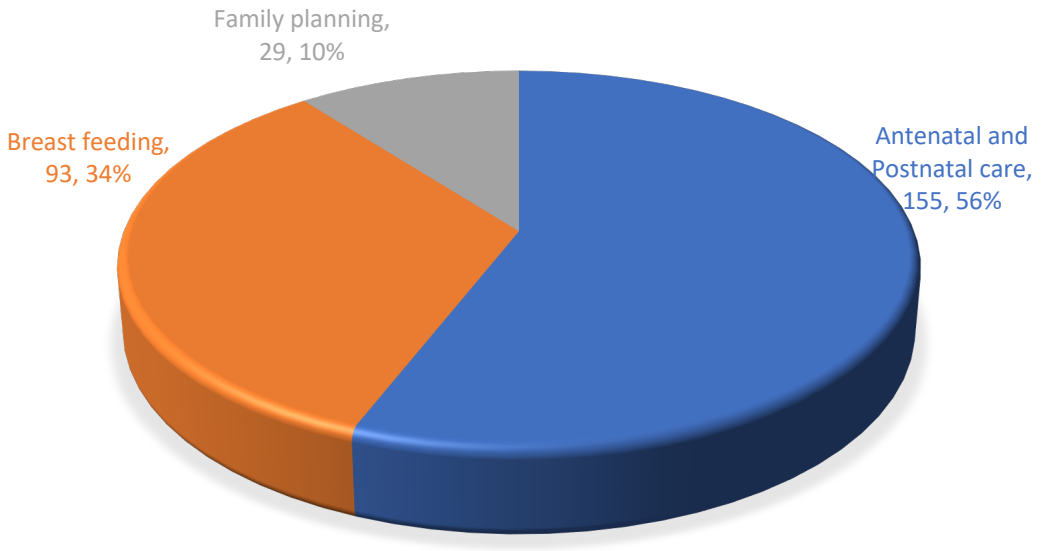

Figure 4.4: Provision of health services specific to women

The majority of CHWs, 80.1% (n=221) who stated that they address health issues specific to women's health were female. Only 3.1% (n=9) female and 2.4% (n=7) male did not feel that the services they provided were specific to women.

Furthermore, it was established that PHC delivery in the town council was supported by the NGOs listed below:

- Makerere University, Uganda
- The United Nations Children's Fund (UNICEF)
- The AIDS Support Organisation (TASO) Uganda
- Different health parastatals
- Protection of Families against HIV/AIDs (PREFA) Uganda
- Medical Research Council (MRC) Uganda
- Malaria Consortium
- Tropical Health and Education Trust (THET)
- Adventist Development and Relief Agency (ADRA) Uganda

4.2 Early Detection Services for Breast Cancer

This section provides findings on the availability and delivery of early breast cancer detection services at the PHC level. It also presents findings on health workers trained to provide early detection services and health promotion activities platforms used.

4.2.1 Availability of breast cancer detection services at the health centres

Generally, early breast cancer detection services provided at the health centres were limited (Table 4.7). Findings from the situation analysis also revealed that none of the CHWs in Kajjansi town council provided early detection services for breast cancer.

Table 4.7: Breast cancer detection services available at the health centres Kajjansi town council

Breast cancer detection services	HC II	HC III	HC IV
Breast awareness	x	✓	✓
Clinical breast examination (CBE)	x	✓	✓
Encouraging breast self-examination (BSE)	x	✓	✓
Population-based mammography screening	x	x	x
Opportunistic mammography screening	x	x	x
Mammography screening as part of a breast screening clinic	x	x	x
Breast ultrasound	x	x	x

Nakawuka HC III and Kajjansi HC IV reported that they provide breast awareness for women and encouraged BSE. Both health centres also indicated that they perform CBE for women with both palpable and non-palpable breast lumps. Specifically, Kajjansi HC IV revealed that CBE was performed during ante-natal and post-natal care. It was indicated that clinical officers and midwives provided these early detection services for breast cancer. It was also established that the nurses in Nakawuka HC III also trained women on BSE and performed CBE.

Nakawuka HC III and Kajjansi HC IV further elucidated that the highlighted breast cancer detection services were being delivered at the health centres through outreach programmes supported by an NGO (name withheld for confidentiality). HC IV also identified another NGO

that supports the delivery of early detection of breast cancer services through outreach programmes at the health centre.

4.2.2 Awareness of breast cancer and breast cancer detection

The CHWs were further asked if they had heard of breast cancer and were aware of how it can be detected. The majority of the CHWs (n=290; 99.3%) had heard of breast cancer. However, less than half of the CHWs surveyed (n=127; 43.5%) were aware of how it can be detected. Out of the CHWs who are aware of how breast cancer can be detected (n=127), the majority (n=108; 85%) were aware of CBE. The number of CHWs who knew about BSE and breast ultrasound as breast cancer detection strategies were 36.2% (n=46) and 45% (n=25) respectively. Only a few CHWs 1.6% (n=2) were aware of mammography screening.

In order to understand if there could be any gender issues in relation to health service delivery among the CHWs for breast cancer detection, they were further asked whether male CHWs could provide breast cancer detection services. The findings established that majority (n=282; 96.6%) of the respondents perceived that male CHWs were unable to provide breast cancer detection services, even though 94.5% (n=276; see section 4.1.2) of the total CHWs surveyed indicated that they provide services specific to women.

4.2.3 Health promotion and education for breast cancer detection

The health promotion and education platforms used by the health centres to disseminate breast cancer detection messages presented in Table 4.8 include CHWs, one-on-one conversation, during immunisation and antenatal clinics and leaflets provided by the breast cancer support NGOs.

Table 4.8: Health promotion and education platforms used to promote breast cancer detection

Health promotion and education platform to promote breast cancer detection	HC II	HC III	HC IV
Leaflets	x	x	Provided by NGOs to disseminate breast cancer information
Posters	X	X	X
Television	X	X	X
Radio	X	X	X

Newspaper	X	X	X
Social media (Facebook, Twitter)	X	X	X
Other (specify):	X	one on one conversation, CHWs (basic knowledge), immunisation and antenatal clinics	X

The health centres were further asked about their health promotion messaging in relation to breast cancer education (Table 4.9). The findings revealed that Nsaggu HC II did not provide any form of breast cancer messages. Through the support of NGOs, Nakawuka HC III and Kajjansi HC IV provided messages relating to awareness of breast cancer risk factors and symptoms. The health centres also indicated that they provide information on how to practice BSE, and the importance of early detection of breast cancer. Information regarding diagnosis, treatment and breast cancer support networks were also provided.

Table 4.9: Health promotion messaging to promote breast cancer control

Health promotion information provided to promote breast cancer care	HC II	HC III	HC IV
Awareness of breast cancer risk factors	X	✓	✓
Signs and symptoms of breast cancer	X	✓	✓
Information about how to practice breast self-examination	X	✓	✓
The importance of breast cancer early detection	X	✓	✓
Outreach/education encouraging CBE for age groups at high risk	X	✓	✓
Diagnosing breast cancer	X	✓	✓
Treatment of breast cancer	X	✓	✓
Information about where to access breast care	X	✓	✓
Information about where to access breast cancer support networks	X	✓	✓
Information about access to financial resources for breast cancer (to pay for diagnosis or treatment, for example)	X	X	X

4.2.4 Training on breast cancer detection

Even though the situation analysis revealed that clinical officers, nurses and midwives in Nakawuka HC III provided training on BSE and CBE services, none of them had received specialised training on early detection of breast cancer. On the other hand, clinical officers and midwives in the HC IV had received specialised training on breast cancer detection as well as cervical and prostate cancers.

All the CHWs surveyed (n = 292) indicated they had received general training to support their roles. Although, majority of the CHWs (n=177; 60.6%) indicated they had received NCDs related training, only one male (0.3%) stated specifically that he had received training relating to breast cancer detection. The CHWs who had received NCDs training said the training was provided by the health centres, the district office, Makerere University, and Adventist Development and Relief Agency.

4.2.5 Referral services

The situation analysis revealed that all the three health centres referred women who present with breast concerns to specialised breast cancer referral centre. Four referral hospitals were identified: Entebbe hospital, Mulago hospital (the National Cancer referral hospital), Kisubi hospital and Mildmay hospital. Estimated distances to these referral hospitals varied (Figure 4.5*)*, for instance, the closest distance to Mulago hospital in Kampala, the capital city is from Kajjansi HC IV which was reported as 6 miles. It was also reported that the only means of transportation available to the women were public transport and private vehicles.

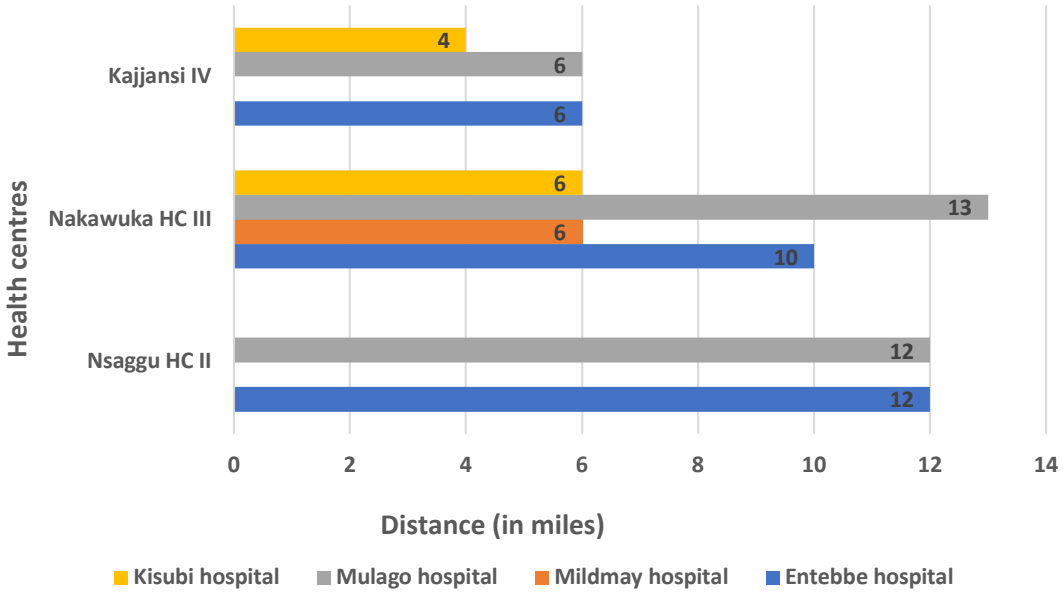

Figure 4.5: Distance to referral hospitals from the three health centres in Kajjansi town council

4.2.6 Challenges to early detection of breast cancer at the primary health care level

Lack of breast cancer detection equipment, inadequate training for CHWs and PHC health workers, insufficient government funding, sex of health workers and lack of a national cancer policy were identified as the predominant challenges faced at PHC level in relation to breast cancer detection. In relation to insufficient government funding, Nakawuka HC III reported that it had been planning to hold a workshop on training for breast cancer detection for its staff but has not been successful due to lack of funds. Furthermore, Nsaggu HC II and Nakawuka HC III specifically stated that the government did not provide funding for breast cancer detection services. In relation to lack of a national policy on cancer, HC IV stated there was no national requirement for the provision of breast cancer detection services at PHC level, hence these services were not required for the level of health centre. The health centres also reported that lack of breast cancer detection equipment, that is, mammogram was a challenge to breast cancer detection. Lastly, lack of privacy due to the examination of the breasts by male health workers was highlighted as a challenge to the delivery of breast cancer detection services. Other challenges highlighted by the health centres include stigma, distance to referral facilities, ignorance at the community level, poverty, and lack of training for staff.

Among the CHWs lack of knowledge about the signs and symptoms of breast cancer (n=290; 99.3%) was highlighted as the predominant challenge to the CHWs' capacities to provide breast cancer detection services. Other challenges identified by the CHWs were lack of breast cancer detection equipment (n=1;0.3%), lack of incentives (n=1;0.3%), and poverty (n=1;0.3%) from a health service utilisation perspective.

4.3 Discussion of the Situation Analysis Findings

4.3.1 Primary health care system in Kajjansi town council

The situation analysis showed a hierarchal structure of the PHC system in Kajjansi town council in Uganda. This structure, which is reflective of the Uganda PHC system, comprises the PHC centres and community health workers. The highest level of health care delivery within the town council is Kajjansi HC IV which sits at the town council level. This is then followed by Nakawuka HC III which is at sub-county level, Nsaggu HC II at parish level, and the CHWs at village level. According to existing literature, the tiered structure from HC I to IV within the town council is regarded as the district level health service delivery system (Acup et al. 2017; Ministry of Health 2014). It can therefore be inferred that the PHC system in Uganda sits within the district level. The different levels of the PHC delivery system further reflect the availability of infrastructure and human resource capacities across various administrative levels in the area. For instance, the bed density which is an important indicator of a health centre capacity and ability to attend to in-patients (Ministry of Health 2014) as was the case for Nakawuka HC III and Kajjansi HC IV. Another key indicator of the health centres capacities used in this study was available human resources. The human resource capacities at the health centres were different from the requirements prescribed on the National District Health Staff Records (NDHSR) (Human Resources for Health Information System n.d.) as shown in Appendix 4.2.

In Nsaggu HC II, the reported number of staff from this study (n=5) exceeded the current number of staff (n=3) recorded on the electronic NDHSR. Although, the health centre II reported having one clinical officer, two nurses and two nursing assistants, the NDHSR showed that it was not required to have a clinical officer and only had requirement for one enrolled nurse. In contrast, Nakawuka HC III did not report having any nursing assistant at the

time of the study despite being a higher-level health centre than Nsaggu HC II. In the case of Kajjansi HC IV, one of the senior medical clinical officers is not an approved but yet filled position. This discrepancy in the number of reported, approved and filled human resources can be explained from two perspectives. First, the situation analysis itself was conducted in 2017 while the NDHSR data presented were retrieved 2019. Hence, it is possible that the current staffing status for the health centres have changed since the data was collected in 2017. Secondly, the discrepancy possibly suggests that the prescribed staffing requirements are not entirely reflective of the staffing practicalities within the health facilities. In relation to the second explanation, a national survey of HC IV reported that generally, health centres IV across Uganda have considerably higher number of staff than those approved (Ministry of Health 2014). Thus, substantiating the explanation that the approved health centre staffing does not necessarily reflect the requirements of the health centres. Therefore, there is a need for the Uganda Ministry of health to ensure that the staffing targets match the needs and requirements at the various health centre levels.

It was also established from the situation analysis findings that the CHWs support with PHC delivery within the town council, and act as intermediaries between the community and other levels of the system. The CHWs do this by serving as health centre I, the first point of entry into the PHC system (Ministry of Health 2010b). The main functions of the CHWs identified from this study align with those articulated in the Uganda *VHT Strategy and Operational Guidelines* which include health promotion and education, mobilisation of communities for utilization of health services and health action, iCCM and home visiting (Ministry of Health 2010b). Although, the guidelines did not indicate referral as a role of CHWs, some of the CHWs who participated in this study reported that they sometimes refer community members to the health centres (n=14; 4.8%). However, lack of an acknowledgement of this role by the Ministry of Health could indicate such referrals are provided informally in an advisory capacity. That said, other studies have also identified referral as a role of CHWs in India (Lehmann and Sanders 2007), Mozambique (Give et al. 2019) and Zambia (Chanda et al. 2011). Even in Uganda, previous studies have shown the ability of CHWs to refer patients to health facilities. For example, a prospective observational study in western Uganda highlights how CHWs referred sick children as part of iCCM (Jarolimova et al. 2018). Therefore, these

evidences suggest that referral is a role of CHWs and should be acknowledged in the Ugandan national CHWs strategy and guidelines.

As seen from the situation analysis, health education is another core role of CHWs with 71.6% (n=209) performing health education roles. This is consistent with the identified roles of CHWs in Uganda (Ministry of Health 2010b) and other African countries such as Kenya, Nigeria and Malawi (Olaniran et al. 2019) and South Africa (Wadler et al. 2011). An interesting finding regarding CHWs roles was the distinction made by CHWs between health education and health promotion. In describing their roles, the CHWs were asked to open-endedly provide a brief summary of what this entails. Although health education is a component of health promotion, both concepts are not interchangeable. While health promotion focuses on enabling people to take control over the determinants of health, health education involves communication of information regarding health and the determinants of health (WHO 1998). From this study, the CHWs highlighted their health promotion roles as distributing essential medicines to community members, deworming children and providing mosquito nets. Whereas their health education roles basically involved providing information around healthy behaviours as established from the situation analysis and previous studies by Raven et al. (2015) and Olaniran et al. (2019). A critical review of these roles suggests that health education on its own, though important to create knowledge, is insufficient to drive healthy behaviours. Health promotion activities are required to facilitate and enable individuals translate the health information received into daily health practices, which subsequently leads to healthy behaviours. For example, in the case of malaria control, the CHWs provide information to the community members on the importance of sleeping under mosquito nets (health education). The health promotion aspect of this comes into effect when CHWs then distribute mosquito nets which enables community members to put the information they have received into practice. Hence, it is important to understand that though health education can be considered as part of health promotion, there are clear distinctions between the two concepts.

In terms of CHWs distribution, the Ministry of Health recommends that each village should have an average of four CHWs (Jarolimova et al. 2018) to five CHWs (Ministry of Health 2010b), which means the town council should have had between 248 (62 x 4) to 310 CHWs

(62 x 5). The implication of this calculation is to show that the existing number of CHWs at the time of the study (n=292) met the national requirement, thus indicating sufficient distribution of CHWs to cover the town council. However, a national survey of CHWs in Uganda reported that about 32% of the villages have lower number of CHWs with an average of 3 CHWs per village (Ministry of Health 2015c). There was also an indication from the situation analysis that the distribution of CHWs had a correlation with the size of health centre. For instance, Kitende parish where Kajjansi HC IV is located had 68 CHWs, the highest across all parishes. The situation analysis further revealed that majority (78.8%; n=230) of the CHWs surveyed were female. This analysis suggests a gendered pattern of CHWs roles in the project area. Although, the Uganda *strategy and operational guidelines* on CHWs (Ministry of Health 2010b) recommended a gender equal distribution of CHWs with at least a third representing women, the study findings showed an imbalance in gender distribution skewed in favour of women. This is consistent with other studies in Wakiso district, Uganda (Bagonza, Kibira and Rutebemberwa 2014), and also agrees with the national trend which has shown that the majority of CHWs in the country are female (Ministry of Health 2015c; Musoke et al. 2018). The higher proportion of female CHWs is not surprising as volunteering as a community health worker is still predominantly considered a female job in most African settings. For instance, a multi-country study on CHWs programme in Uganda, Democratic Republic of Congo, Ghana, Zimbabwe and Senegal reported that CHWs were more likely to be female (Raven et al. 2015). One of the reasons cited for this was in relation to their status as carers in their homes (Raven et al. 2015). The of sex health workers is an important determinant of access to health services as it influences health service utilisation (as discussed in literature review section 2.7) and the nature of health service provision as further discussed in the following section.

4.3.2 Health service delivery at the primary health care level in Kajjansi town council

The major health services targeted at the PHC level were communicable diseases including malaria, HIV/AIDs, tuberculosis, pneumonia, diarrhoea, sexual health, family planning, and maternal and child health. Consequently, PHC services in Uganda and other parts of SSA are still oriented towards addressing these communicable diseases (Asiki et al. 2018) and maternal and child health related issues. The situation analysis identified that all CHWs provide general health services like malaria (n=292) and HIV/AIDs (n=291). Some CHWs also

have an additional responsibility for providing specialised services (n=113), focusing on childhood illnesses for children under five. The existence of this specialised cadre aligns with the categorisation of CHWs in literature into generalist and specialist CHWs (Koon, Goudge and Norris 2013; Lehmann and Sanders 2007). Whereas generalist CHWs have a broader scope and cover a wide range of diseases, specialist CHWs are purposively deployed with skills sets to address specific diseases (Koon, Goudge and Norris 2013) such as maternal and child health (as was the case of the iCCM cadre in this study) and nutrition programmes (Koon, Goudge and Norris 2013). However, there is still a gap in the use of specialist CHWs for breast cancer control as the role of CHWs in NCDs management is still a developing area (Jeet et al. 2017). Another prominent finding was that health care delivery at the PHC level was supported by NGOs. From the list of NGOs outlined (section 4.1.2), it is evident that the NGOs specialities/areas of interest are in congruence with the health services of focus in the town council, notably malaria and HIV/AIDs. This correlation raises a key question around the implications of NGOs support: are these NGOs responding to or shaping the health needs of the communities? The implications of NGOs' influence are further discussed in the qualitative chapter section (7.4.1).

The study also considered the gendered aspect of PHC service delivery by asking CHWs whether they provide services which target women as key recipients. The services identified as being specific to women were related to antenatal and post-natal care, breastfeeding and family planning. These services evidently relate to women in their capacities as mothers. In communities such as in Uganda and SSA in general, women's identities are still largely contextualised around their roles as wives, mothers and caregivers (Remennick 2006). Therefore, it is not surprising that health services which target women specifically focus on their gendered roles as mothers. That said, these services can potentially serve as entry points for the integration of early detection service for breast cancer. Though, these services are focused on women, it does not imply that men should not be involved. For example, a cross-sectional study conducted in Tanzania showed a high level of male involvement in ante-natal care (Gibore, Bali and Kibusi 2019). However, the reverse is the case for Uganda where male involvement in maternal and child health has been reported as low (Muheirwe and Nuhu 2019; WHO African Region 2014). This low rate of involvement prompted the Uganda Ministry

of Health to launch its *National Male Involvement Strategy* to improve male involvement in maternal health (WHO African Region 2014). Therefore, it is important to strengthen male involvement in health services directly related to women (ante-natal, postnatal, family planning, breastfeeding, and breast cancer) to improve uptake of those services.

4.3.3 Primary health care services for breast cancer detection

The situation analysis established that the PHC system in Kajjansi town council was not oriented towards providing organised breast cancer detection services. However, the health centres III and IV have been supported by NGOs to deliver breast cancer detection programmes on CBE, breast cancer awareness and encouraging BSE. Since the NGOs play a critical role in breast cancer detection at the PHC level, they were included as a target participant in the qualitative phase of this study. The three health centres further indicated that they were able to refer issues relating to breast cancer to the regional or national referral hospital. The lack of organised breast cancer detection services at the health centres, and referral to secondary or tertiary hospitals is consistent with findings from other SSA countries such as Nigeria (Oluwatosin 2012), Kenya (Sayed et al. 2019) and Mali (Frie et al. 2019). Furthermore, among the CHWs, none of them provided breast cancer detection services. Even though almost all the CHWs (n = 290; 99.3%) were aware of breast cancer, only 43.5% (n=127) of them knew about any breast cancer detection strategies. This finding confirms findings from a previous study which revealed that women in Kajjansi town council had heard of breast cancer but there was low knowledge about how it can be detected (Ilaboya 2015). This further implies that there is a need to educate and increase the knowledge of CHWs around breast cancer detection. This need for educating and training CHWs in breast cancer detection aligns with the increasing recognition of the importance of CHWs for NCDs management (Jeet et al. 2017; Neupane et al. 2014). However, despite this recognition, limited studies exist on the potential of CHWs in NCDs management, particularly for breast cancer detection in low income SSA countries (Pace et al. 2018). Therefore, the potential role of CHWs in the promotion of breast cancer detection was further explored during the qualitative data collection.

Although, Nakawuka HC III indicated that it provided breast education for women during antenatal and immunisation clinic, this was not the case in Kajjansi HC IV. Kajjansi HC IV would usually be expected to provide a wider breadth of health services than Nakawuka HC III and Nsaggu II as it represents the highest level of health service delivery within the PHC system in the town council (Ministry of Health 2014). On the other hand, it may be assumed that the response provided by Nakawuka HC III related to the NGOs as the health centre did not provide organised breast cancer detection services. So, the qualitative phase also sought to clarify this finding and better understand the nature of breast cancer detection services provided by the HC III and IV. Even though Nakawuka HC III also reported that its clinical officers, nurses and midwives were able to provide CBE and teach women on BSE, none of the staff had received specialised training on breast cancer detection. On the other hand, the situation analysis showed that while clinical officers and midwives in Kajjansi HC IV had received specialised training on breast cancer detection as well as cervical and prostate cancers, the three top cancers in the country (Ferlay, et al. 2018), they did not provide breast cancer detection services. The implication of this finding is that gaps may exist in knowledge translation to practice in the case of Kajjansi HC IV. Hence, the qualitative component of the study further explored how to enhance the capacities of PHC workers towards promoting early breast cancer detection in Uganda.

4.3.4 Challenges of early breast cancer detection

This section discusses the challenges of early breast cancer detection as identified from the situation analysis. These challenges include ignorance of health service users, stigma, lack of breast cancer monitoring system, poverty, lack of mammography screening, inadequate training for health centre staff and CHWs, inadequate incentives for CHWs, distance to health centres, sex of health workers, lack of national cancer policy and funding constraints. Although these challenges were highlighted from a PHC service delivery perspective, they are consistent with challenges discussed in the literature review (section 2.7) which were mostly from women, health service user and policymakers' perspectives. That said, the situation analysis expands on the existing body of knowledge through identification of challenges from a PHC perspective. To date, this is the only study known to the researcher following extensive literature review that has investigated breast cancer detection challenges in Uganda from

both CHWs and PHC staff in a single study. Previous studies around breast cancer detection challenges in Uganda have predominantly focused on women (Ikhile, Gibson and Wahidin 2019; Koon, Lehman and Gralow 2013; Scheel et al. 2017) who described challenges from a service user perspective. For consistency, the identified challenges are discussed in alignment with the different levels of the socioecological model. The only individual and community levels challenges identified during the situation analysis were ignorance of service users and stigma respectively. These challenges have been extensively discussed in section 2.7 of the literature review chapter, hence no further discussions on ignorance of service users and stigma are included in this section.

In relation to the organisational challenges, inadequate knowledge among CHWs, inadequate training of PHC staff, lack of breast cancer monitoring system, and lack of mammography screening were identified as the main challenges to breast cancer detection at the PHC centres. Mammography screening is not a recommended strategy for Uganda and other SSA countries as it is not readily available (Black, Hyslop and Richmond 2019; Gakwaya et al. 2008; Pace et al. 2018) mainly due to its high resource intensiveness (WHO 2017a), hence not a challenge that can be feasibly addressed for the Ugandan context. Inadequate training of PHC workers results in inadequate knowledge especially among CHWs as evident from the situation analysis, thus preventing them from being able to sensitise community members on breast cancer awareness. The term PHC workers is being used as a broad term for CHWs and the health centre staff. Inadequate knowledge has been previously evidenced generally among PHC workers in Mali (Frie et al. 2019) and Rwanda (Martin et al. 2019). However, given the important role of PHC workers as the first point of entry into the healthcare system (WHO 2018c), there is a need to provide them with the knowledge required to create breast awareness within their various communities. Therefore, the qualitative aspect of this study provides evidence on how the knowledge gap for CHWs and PHC workers can be bridged. The CHWs further identified inadequate incentives as another organisational challenge. Although there is a dearth of literature on how inadequate incentives affective CHWs performance in relation to breast cancer, various literature exists articulating how lack of adequate incentives affect how CHWs generally perform especially in SSA settings (Haile, Yemane and Gebreslassie 2014; Miller et al. 2014; Ormel et al. 2019). As established in the literature

review (section 2.4.1), the CHWs are health volunteers who provide supporting roles as part of the formal health system. Since they do not receive formal renumeration, they largely depend on financial and non-financial packages as a form of motivation and compensation for their services.

Another organisational challenge evident from the situation analysis findings was the lack of breast cancer records and tracking system. Although HC IV estimated that about ten women attend the health centre monthly for breast health concerns, it could not provide an estimate of women who have symptoms of breast cancer or women with suspicious findings who do not return after their initial consultation. This raises the question of if breast cancer is suspected/detected, what happens? Since there is no follow-up system in place. Although the number of women attending HC IV monthly for breast health concerns is quite low (n=10), this can be attributed to a number of reasons. For example, low awareness, distance to the PHC centres, fear and stigma. Another reason could be because some women with breast concerns bypass the PHC centres for tertiary hospitals (Ilaboya 2015; Frie et al. 2019). Therefore, this figure (n=10) may not be an accurate representation, as Kajjansi HC IV lacked a cancer-based recording system to monitor breast cancer cases. However, the figure becomes significance if recorded over a period of time. This lack of adequate monitoring system for cancer is a major challenge for cancer control across SSA generally as it means that the true magnitude of the burden for this disease remains unknown (Pace and Shulman 2016). This challenge is also reflective of the national trend where the country has an inadequate national cancer monitoring system. The challenge of an inadequate monitoring system is discussed as an organisational level challenge in this chapter, whereas it was discussed at the policy level in the literature review chapter. This is because the literature review focused on the national cancer monitoring system while this chapter specifically focused on breast cancer monitoring at the PHC centres. The conceptualisation of inadequate monitoring system as an organisational or policy level challenge further buttress the point that the socioecological model is fluid and the different levels interact. Furthermore, the availability of paper-based records in all three health centres is consistent with findings from a PHC capacity assessment conducted by Mendis et al. (2012) in ninety health centres across eight low-and-middle-income countries which revealed a lack of an organised referral system for effective medical

tracking and follow-up. As established in the literature review, the lack of a monitoring and follow-up system is an impediment to effective breast cancer control in Uganda. Therefore, there is a need for an accurate monitoring and follow-up system to be put in place in order to ascertain the true burden of breast cancer in Uganda.

Poverty, distance to referral hospitals and gender norms around sex of PHC health workers were the structural challenges identified during the situation analysis. The situation analysis findings revealed that women had to travel between 6 to 12 miles (approximately 10 to 21km) to access breast cancer services. This has direct implications on finances as travelling longer distances imply higher cost of transportation (Peters et al. 2008), which women may not be able to afford. Despite being able to refer women, the health centres did not provide transport facility to support continuity of care which means women rely on public transport and private vehicles. Due to the high level of poverty in the rural parts of Uganda (World Bank Group 2018), it can be assumed that the majority of these women would rely on public transport as their means of transportation. The reliance on public transportation is problematic due to poor road conditions (Ilaboya, Gibson and Musoke 2018) and cost of transportation. which restricts ease of access. These challenges of poverty and distance have impacts on general health care delivery (Madinah 2016; Varela et al. 2019; Wong et al. 2020). For instance, Varela et al. (2019) reported how long distance, inadequate transportation and financial constraints mitigate access to surgical services for rural inhabitants in Malawi. In the case of Uganda, even if breast cancer detection services were available at the PHC centres, a woman would still have to travel long distances upon referral to regional or national hospitals in order to access diagnostic and treatment services. Therefore, this indicates that poverty and distance do not only affect breast cancer detection but has implications for access to follow-on breast cancer management services.

During the situation analysis, two NGOs were identified that directly support the health centres with the delivery of breast cancer detection services. Nevertheless, this in itself can be problematic as there are sixty-two villages within the project area. Therefore, only women in close proximity to these health centres would have access to and benefit from such services. This challenge of far proximity to the health centres can be addressed by CHWs (Javanparast et al. 2018), thus, further highlighting their significance in promoting access to

health services. In relation to the sex of PHC workers, the perceptions of the majority of the CHWs that the male among them are unable to provide breast cancer detection services could be attributed to gender norms around health service delivery. Thus, emphasising the gendered nature of PHC delivery. Sex of CHWs is an important factor in this context because it relates directly to gender as a determinant of access to health (Hankivsky 2012). This confirms findings from previous studies in Uganda (Ilaboya 2015), Kenya (Sayed et al. 2019) and Malawi (Kohler et al. 2017) where women reported that they would not feel comfortable having a male health worker palpate their breasts or talk to them about breast cancer. These previous studies confirm the cultural structures in most SSA settings where it is considered culturally inappropriate for a woman to openly discuss or allow the opposite sex who is not her partner examine her breasts (Asobayire and Barley 2015; Tetteh and Faulkner 2016). Therefore, there is a need to ensure that breast cancer detection programmes are context-appropriate, cognisant of this culture, and do not restrict women's access to breast cancer detection services.

At the policy level, insufficient financial support from the national government and lack of a guiding national cancer policy were identified as challenges affecting PHC delivery for early breast cancer detection. As seen from the situation analysis findings, the health centres still lacked the basic and essential infrastructure such as alcohol hand rub, stand by generators in case of power outages. Lack of these basic infrastructure depicts the extent of financial constraints faced by these health centres. This infrastructural challenge poses limitations on the PHC and national health systems and impedes the effective delivery of breast detection services (Adeloye et al. 2018). Although the Ugandan *Health Sector Development Plan* 2015/16 – 2019/20 (Ministry of Health 2015a) recognises the increasing burden of NCDs, there is no guidance on breast cancer control service provision at the various health care level as indicated by Kajjansi HC IV. The NCDs control guidance provided in the *Health Sector Development Plan* is generic, so, a focused plan or guideline is required for cancer. The country has a strategic plan in place for cervical cancer control (Ministry of Health 2010c) which is estimated to be the most common cancer affecting women in Uganda (Ferlay et al. 2018). However, a lack of national guideline for breast cancer implies low prioritisation of this disease in comparison to cervical cancer. It is important to clarify that a guideline on breast

cancer does not necessarily have to be a separate document, as it can be integrated within a comprehensive national cancer control plan as recommended by the WHO (2006). That said, Uganda does not have a national cancer control plan, as discussed in the literature review (section 2.7) and reaffirmed during the situation analysis. Therefore, it is recommended that the Ugandan Government puts effort into developing a national cancer control plan with clear guidance for the control of breast cancer and other common cancers in the country.

4.4 Implications of the Situation Analysis Findings for the Qualitative Phase

This section shows how the quantitative findings relate to the qualitative phase, specifically how they informed the development of the interview questions for the qualitative data collection. The findings from the situation analysis were important in establishing the limited availability of breast cancer detection services at the PHC level in Kajjansi town council. It further highlighted the gap in PHC service delivery relating to early detection of breast cancer. In relation to availability, the situation analysis revealed that the existing breast cancer detection services in the town council have been provided through the support of NGOs. The three health centres and CHWs did not provide services for breast cancer detection. Thus, women were mostly referred to secondary and tertiary hospitals. The situation analysis further highlighted four critical findings in relation to the PHC system: the presence of a structured PHC system; the significance of CHWs in PHC delivery; current health services which can potentially serve as entry points to integrate breast cancer detection; breast cancer detection challenges from a PHC perspective. As a result, the qualitative phase of data collection focused on explaining the following:

Capacity building of CHWs: A major finding from the situation analysis was the key roles of CHWs in relation to PHC delivery. The contributions of CHWs to communicable diseases management can arguably be said to have a direct impact on the reduction of their burden in Uganda. For instance, Baatiema (2016) highlighted the roles of CHWs in the attainment of the 2000-2015 millennium development goals as well as their potential contribution towards the attainment of the SDGs. However, the situation analysis identified that they do not provide early breast cancer detection services due to gaps in their training and capacity. Therefore,

the qualitative data collection phase sought to understand the CHW's roles and how to build their capacity to enable them to deliver early breast cancer detection services.

Integration of early breast cancer detection with existing services: Though the situation analysis revealed that the health service delivery at the PHC level focused predominantly on communicable diseases, some of these services were highlighted as being targeted specifically at women. Those services which target women specifically as well as those which target the whole community can potentially serve as entry points for early breast cancer detection. The qualitative data explained how early breast cancer detection could be integrated with existing health services.

Provision of organised breast cancer detection services within the primary health care service delivery system: Existing services relating to breast cancer detection were programme-based and not integrated within the PHC delivery system. The implication of this is that services were not organised and embedded within the government health system as they were delivered by NGOs. These NGOs programmes which are usually bound by time and funding (Arhin, Kumi and Adam 2018) are generally not sustainable. Therefore, the qualitative data collection provided insights into the resources required to put in place for organised early breast cancer detection services within the current PHC system. Furthermore, interviews with NGOs representatives were conducted during the qualitative phase to understand how they operate with the existing healthcare system and their contribution to PHC driven early breast cancer detection.

Engaging women in the delivery of early breast cancer detection services: From the situation analysis, CHWs and the health centres reported that they engaged with community members who are recipients of PHC services through household visits, community gatherings, consultations from community members, posters etc. Since women are the key target group in breast cancer detection, the qualitative phase sought to understand how the PHC system can engage with them for the delivery of early breast cancer detection services.

Addressing the challenges to breast cancer detection in Kajjansi town council: The challenges identified from the situation analysis were consolidated with those analysed in the literature review. Practical solutions to these challenges were then explored during the

qualitative phase. The consolidated challenges are presented through a socioecological model in Figure 4.6. A detailed breakdown of the challenges and how they were used in the design of qualitative data collection phase is provided in Appendix 4.3.

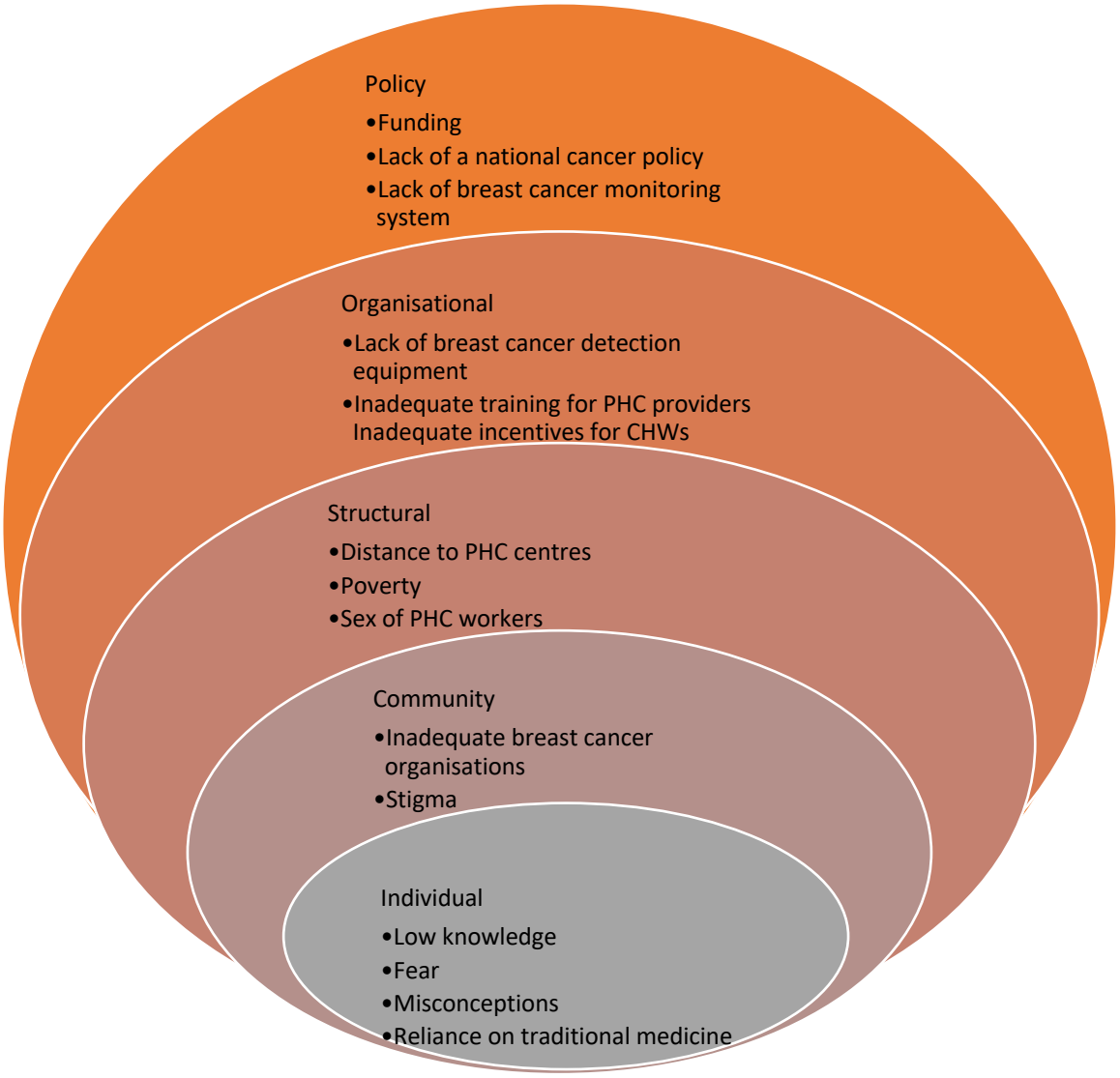

Figure 4.6: A socioecological model showing challenges to early breast cancer detection

A summary of how the situation analysis findings informed the qualitative data collection questions (Appendix 3.4) is presented in Table 4.10.

Table 4.10: Summary of how the quantitative findings informed the qualitative data collection

Intervention areas defined through the situation analysis	Qualitative data collection questions
Addressing the challenges to early breast cancer detection in Kajjansi town council	• In your opinion, what are the solutions to the identified challenges? • Are there other challenges associated with early detection of breast cancer that you would like to discuss? What are the solutions to these challenges?
Provision of organised breast cancer detection services within the PHC system	• How can the PHC capacity be strengthened to deliver breast cancer detection services? • How can you [health centre, district health team, NGO, Ministry of Health] contribute to the early detection of breast cancer? • In your opinion, what resources are required to promote early detection of breast cancer for women?* • Who do you [NGOs] work with and how do you work with them [CHWs, health centres, government officials, etc.]? • How do you [NGOs] carry out your health projects/programmes? [Through health centres or do you go directly to the communities?] • What would be feasible for breast cancer detection at the primary health care level? How can the government [Ministry of health] support with this?
Integration of early breast cancer detection with existing services	• How can existing primary healthcare services support early detection of breast cancer for women?
Capacity building of CHWs	• How can CHWs support with delivery of early detection services for breast cancer? • How can the government support CHWs to provide breast cancer detection services? • In your opinion, what resources are required to promote early detection of breast cancer for women?*
Approaches to engage women in breast cancer detection	• How can women be engaged to promote early detection of breast cancer? • How are health services delivered to meet the needs of women?

*This question is repeated as it applies to both themes.

Chapter Summary

This chapter presented and discussed findings from the quantitative data collection - the situation analysis. The situation analysis revealed that services for early detection of breast cancer in Kajjansi town council were limited. A key finding from this analysis was that although CHWs are instrumental for promoting health in relation to communicable diseases, their role

in the early detection of breast cancer was non-existent. The situation analysis further identified the challenges of providing breast cancer detection services from PHC perspective. Given the findings identified in this chapter, the qualitative data collection was conducted to examine how breast cancer detection services can be improved to fit the context of the project area. The next chapter presents the analysis of findings from the qualitative data collection, which examined how the existing PHC capacity can be strengthened to promote early detection of breast cancer.

CHAPTER FIVE

5.0 QUALITATIVE FINDINGS I

In this chapter, I present the findings that emerged from the qualitative data collection phase of this study. The situation analysis (chapter four) established that the three PHC centres in Kajjansi town council did not provide organised breast cancer detection services. However, Nakawuka HC III and Kajjansi HC IV were supported by NGOs to provide breast cancer awareness, CBE and train women on BSE. Thus, the qualitative phase of this study was designed to gather practical evidence on how these breast cancer detection services can be provided within the existing PHC system in order to promote sustained breast cancer detection in the town council. The focus of the qualitative data collection was beyond asking participants for generic recommendations but seeking to understand how suggested solutions can be practically implemented. Therefore, the qualitative phase was specifically conducted to:

1. Elaborate on the findings generated from the quantitative phase;
2. Identify practical solutions to existing challenges around early breast cancer detection in Kajjansi town council;
3. Examine what and how to strengthen the primary health care system in Kajjansi town council to deliver early breast cancer detection services.

5.1 Presenting the Qualitative Data

I used Braun and Clarke's (2006) thematic analysis to analyse the qualitative data. From the thematic analysis, I identified six main themes which encapsulate a number of sub-themes that provide richer insights into the essence of the main themes. As recommended by Braun and Clarke (2006), I further developed a thematic map to visually show the main themes as shown in Figure 5.1.

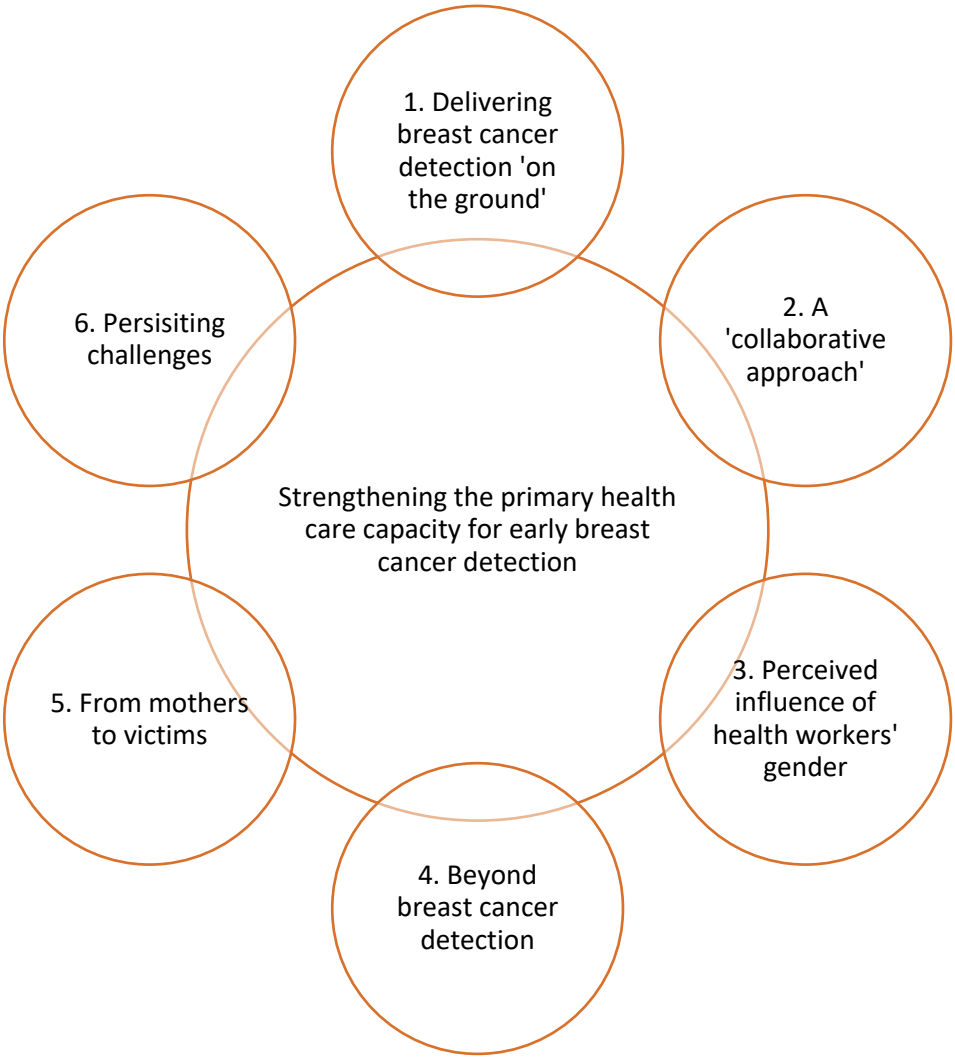

Figure 5.1: An illustration of the themes from the qualitative data analysis

The following bullet points outline the key considerations guiding my presentation of the qualitative findings:

- The data are presented using both illustrative and analytic approaches.
- In naming the themes and sub-themes, where appropriate I allowed the data itself to generate names for the themes. These are presented in single quotation marks.
- In abiding with my ethical commitment of ensuring confidentiality and anonymity of participants and as stated in the methodology (section 3.4), pseudo names for study participants are used at the end of data extracts.
- Where appropriate, the sex of the participant is specified to draw out the gendered nuances around their responses.

- Data extracts which are single, or a couple of words and less than two lines have been weaved into the narrative in italics while those more than two lines are presented as standalone extracts.
- Where appropriate, the data extracts are presented as a dialogue between me and the study participant.
- The themes and sub-themes are qualified using some, all, majority or most. The qualification or quantification of qualitative data in thematic analysis has been recognised by Braun and Clarke (2006) as being based on the researcher's preference to describe the prevalence of a theme or sub-theme.
- Breast cancer detection services referred to are those established from the literature review (section 2.3.1) and situation analysis chapter (section 4.2) as applicable to Uganda. These include breast cancer awareness, BSE and CBE.
- PHC worker is used as an umbrella term to refer to health centres workers and CHWs, while PHC staff is used to refer to health centres workers only.
- Lastly, to aid easy reading, I have broken down the six themes across three chapters as follows:
    - Chapter five (Qualitative Data Findings): Theme 1
    - Chapter six (Qualitative Data Findings II): Theme 2
    - Chapter seven (Qualitative Data Findings III): Themes 3 – 6

5.2 Delivering Breast Cancer Detection Services 'on the ground'

The first theme I identified from this study focuses on delivering breast cancer detection services on *the ground*. Majority of the participants either referred to bringing breast cancer services 'on the ground', *to the ground*, *down to the village*, *village level* or *the community down there* as a way of making breast cancer detection services available and accessible at the community level, within the town council. The theme, delivering breast cancer detection services 'on the ground' encapsulates a double-pronged approach to provide breast cancer detection services both at the primary health centres and at the community level.

Mike: Maybe to bring those [breast cancer detection] services closer to the ground.

Int: So closer to the ground how? In what form?

Mike: So, the services can be brought from the hospitals to health centres IV and IIIs

Mike's (CHW) quote above makes reference to delivering breast cancer detection at the town council by taking early breast cancer detection services from hospitals and providing them through the PHC centres. This was reinforced by Alice, another CHW who indicated that breast cancer detection services can be delivered 'on the ground' by *extend[ing] breast cancer services to…[the] health centres in the villages.*

Alice's use of the word *extend* mirrors Mike's suggestion and indicates that while early breast cancer detection services are not currently provided at the PHC centres, they are available at hospitals outside the town council. However, the majority of the participants placed emphasis on providing early breast cancer detection services 'in' the community as opposed to having women go to the health centres. The importance of this, as explained by Mark in the quote below is to ensure that breast cancer detection services target the whole community, not just the *sick population* as people only tend to visit the health centres when they are sick.

> *You realise somebody who comes to the health facility is already either sick or is already expecting to be sick. So, if you are focusing on people who come to the facility you are leaving a big chunk of community members who do not come to the facility because after all they don't feel sick and remember that cancer of the breast, I know is one thing that will not easily just come and today or tomorrow somebody is sick. By the time we wait for these mothers to come to the facility it is now a big problem. So…we need also to have those interventions that will reach out to people in the communities. (Mark, district health team representative)*

This first theme consists of three sub-themes: leveraging on the existing primary health care system, community outreach and resources (Figure 5.2). Analysis of these sub-themes is presented in the following sub-sections.

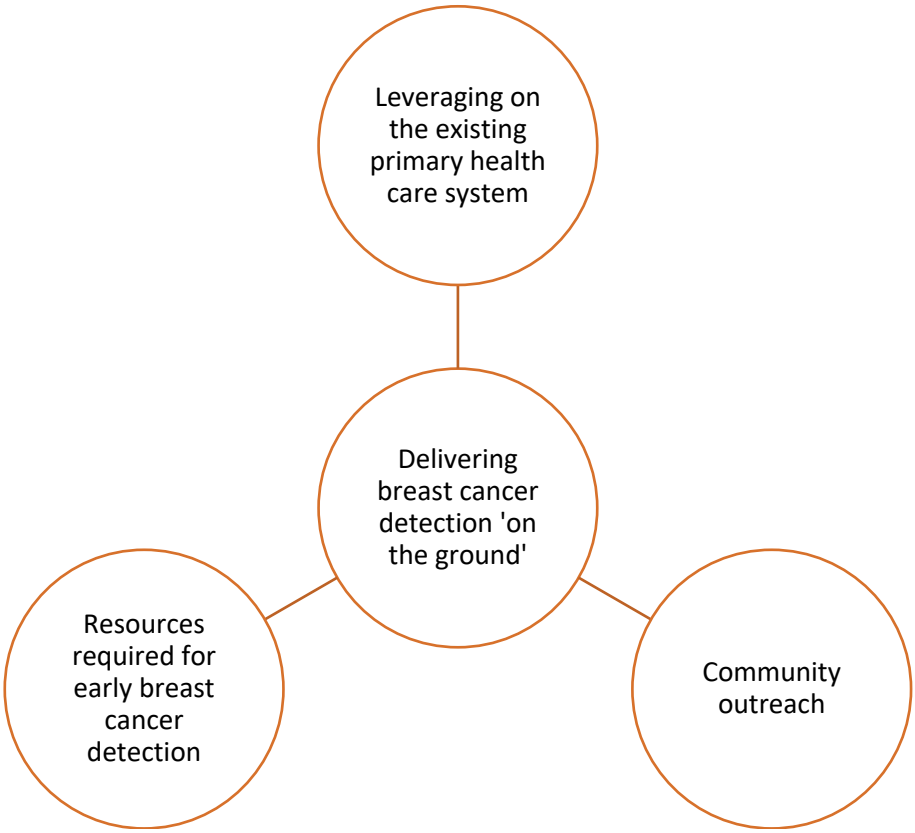

Figure 5.2: Illustration of sub-themes within delivering breast cancer detection services 'on the ground' theme

5.2.1 Leveraging on the existing primary health care system

At the health centre level, the study participants established that breast cancer detection services can be provided by leveraging on the existing primary health care system. Two pathways were identified for leveraging on the existing primary health care system: integration of breast cancer detection in the existing PHC system through *riding on existing services* or having *scheduled routine [breast cancer] clinic [Mark, district health team representative].*

'Riding on existing [primary health care] services'

All the study participants revealed that breast cancer detection services can be provided by integrating with existing health services offered at the health centres or by CHWs. Specifically, the study showed that breast cancer can be integrated with services like *family planning because these are mainly mothers so family planning can be integrated* (Agnes, district health

team representative. Also, services like *ART [Antiretroviral] for HIV, immunisation, ante-natal, post-natal and laboratories as women go to all these places* [Alice, CHW].

> *Right now, we have a certain programme that we are implementing on family planning in the district. So, when you look at for example the family planning where many mothers always come…we can ride on an existing programme like this family planning. Even there are those other programmes that are regular, there are those other NGOs and community-based organisations who have different packages. We have ARTs programme, that is happening in almost all the facilities excluding health centre IIs. So, that means that those existing programmes within our respective communities and within our respective areas are good enough to ride on such a programme...But remember that most of these programmes are already existing at the health facility level. So, we just need to see how to link up with this existing structures and programmes to direct the communication to the respective community members. [Also] through the midwives at these health facilities, at least if a woman will not visit the health facility, at least at one point in her life when she's pregnant, she must visit the facility so if she visits the facilities, if the midwives are skilled enough to include it [breast examination] as part of the parameters that they have to check then I think it can save us from this cancer. (Mark, district health team representative)*

In the quote above, Mark provides a clear summary of how leveraging on existing health services would work for the health centres. He refers to *rid[ing] on [the] existing programme* meaning there is no need for setting up a new programme for breast cancer detection. Rather, breast cancer detection can be provided as an add-on service integrated into the existing PHC services.

CHWs also stated that they can also provide information about breast cancer when they are being consulted on other health issues. For instance, Alice (CHW) explains that she can share breast cancer information with a woman when she brings *her child to be treated for malaria*. In the quote below, Kate also points out that she can provide breast cancer detection information to a mother who brings her child for monthly immunisation.

Yea, in our community we have immunisation which is usually done every month so…when they [women] come for immunisation, you can counsel them at least give them little information about breast cancer that it is curable when it's at an early stage. (Kate, CHW)

Scheduled breast cancer clinics

In contrast to 'riding on existing programmes', the study revealed that another way of delivering breast cancer detection at the health system level is to learn from the existing practice of having scheduled clinic day for different health issues at the health centres. For example, the findings indicated that health centres in Kajjansi town council have scheduled clinics for ante-natal and antiretroviral therapy (ART) for HIV. As such, breast cancer detection services can be provided at the health centres through scheduled breast cancer clinic days as suggested by most participants.

Like the health centres they also have their programmes. Like you may find out that on Monday it's basically the ante-natal whatever, it's all about pregnancy. On Tuesday, it's all about ART clinic day. So, if they also set up a day like on Thursday people just come in for cancer training and check-ups at least people from the village they just know that every Thursday they go for the medical check-up, go for the information. Someone can just set a date that this Thursday I am going to the health centre for that [breast cancer detection programme]. (Anita, CHW)

Contrary to 'riding on existing services' which does not require setting up a new system, putting in place a scheduled breast cancer clinic requires reorienting the current health system structure and putting in place a new programme for breast cancer detection as evident from Anita's quote. However, understanding that the health centres already have full schedules, I further asked how the health centre would manage the additional workload of a breast cancer detection programme. Caroline's [HC IV representative] response below shows that the health centres can manage with a breast cancer detection programme through proper allocations of duty to their staff.

Int: So how can you manage this [scheduled breast cancer clinic] on top of your existing workload?

Caroline: I think what we can do, that can be the duty allocations at the facilities. If at all there is an activity around breast cancer on a particular day, then we can allocate some staff to that duty for that day, I think it can work.

5.2.2 Community outreach

The Community outreach sub-theme represents how breast cancer can be delivered at a community level. As established from the study, community outreach involve taking breast cancer detection services to the women at the community level as opposed to the women visiting the health centres.

Mostly, we need to organise those outreach[es] to meet the women, talk to them to know about [breast] cancer. What are the causes, if someone is found with [breast] cancer what is the way forward? So, like when we talk to them, they get to know about breast cancer. Some people in those villages they know nothing about breast cancer, so we have to meet them, discuss with them and teach them about that [breast] cancer. They will then manage to know. (Mike, CHW)

Mike's use of the qualifier 'mostly' indicates a preference for providing early breast cancer detection services for women through community outreach rather than visiting the health centres. According to Agnes [key informant], taking breast cancer detection services to community level will take away accessibility challenges for those women who *don't have transport to go to the health facility* and those who lack the time to visit the health centres.

So, instead of these mothers the ones who are saying you know what I don't have transport to go to the health facility, we bring the [breast cancer detection] service nearer to their places of stay and places of work. Because once you bring a service in the market, and there's no market where a mother will not come to be screened because she will not have the excuse of saying I'm leaving my merchandise to go and stay at the health facility the whole day. (Agnes, district health team representative)

Specifically, in the quote above, Agnes alluded to delivering breast cancer detection to women in the market, as most women frequently visit the market. According to Agnes, taking breast cancer detection service to the market will take away any constraints or excuse of not being able to attend the health centre for breast cancer detection.

Stanley (CHW) further elaborated that it is not just about organising community outreach but ensuring that they are organised regularly. In the quote below, Stanley suggested monthly outreach rather than the quarterly outreach which is the current practice in the town council.

> *And another thing we can do at least to make outreach numerous not quarterly because we do quarterly. Every 4 months we do outreach, so you find out that within a year we have only 3 outreach[es] within the community. But if at all we do at least every month because for us as VHTs we go on sensitising people about various diseases, various whatever about health and enable them at least to come to know that such a symptom it means I may have such a disease so let me ask the VHT at least to guide me on what to do. (Stanley, CHW)*

In order to implement an effective outreach, Beatrice (CHW) highlighted the importance of using insiders, that is, existing community members such as the CHWs and not bringing in outsiders.

> *Beatrice: Okay, sometimes they use the very people in that village, but they don't say that if you are in Kampala you go to Kasanje. They use the very people in that village.*
>
> *Int: Okay, but what is the importance of that, what is the value of using people from the village?*
>
> *Beatrice: It is better to use people from the village- if people have fear, they tell you the real truth. Sometimes people fear to talk to people from very far, they ask why does this one want to know this about me? So, we people in the village, we know those people very much, we talk to them properly and tell you their problems. But sometimes these people fear to talk to people who are very far, but people who are in that village, they know the people, they know that this one is this, they can tell you the real truth.*

One key value of this is that community members trust insiders to share the 'real truth' about breast cancer with them. Whereas, as Beatrice suggested, women could be wary about opening up to an outsider.

5.2.3 Resources required for early breast cancer detection

The study findings further established that delivering breast cancer detection 'on the ground' requires the following resources: funding, knowledgeable health workers, multimedia resources and policy requirements.

> *Emmm, like they can give us finances and knowledge. Some of us, they lack knowledge about breast cancer they need to be trained they need to be trained because most of our VHTs they have not got even the chance to get that training. Not all our VHTs have got the chance to attend these training whereby some of the women in the villages can come and approach her, ask her or him questions so him or her cannot give her the quality response because him or her is still ignorant about cancer. (Mike, CHW)*

Knowledge

From the study findings, knowledge was constructed as a resource to promote early detection of breast cancer as seen from Mike's quote above. In order to obtain knowledge, participants stressed the need to *sensitise*, *create awareness, teach* or *educate* everyone about the importance of breast cancer detection.

> *Another resource is just to educate people because the major thing, what I know the major thing is ignorance. If people know, we can avoid everything. Some people they can get to know that they have breast cancer when it has already matured but the awareness helps if someone shows the signs and symptoms you can say it is near the signs of what they told us about breast cancer. But some people they realise that they have breast cancer when it has already matured. So, sensitisation, making people know, if people know the signs and symptoms of breast cancer, they can decrease on the people who are dying of that. (Steve, CHW)*

The study findings further established that breast cancer knowledge should be provided through community-wide health education which should be targeted at women, men, community leaders and PHC workers. For instance, Sharon (key informant) stated that: *So, it should be all, you know the politicians are educated, the health workers, the community, the patients themselves for self-care, self-examination, the VHTs of course*.

The study specifically suggested that knowledge is integral to driving behaviour change, as highlighted by Vincent (in the quote below) and Constance (CHW) who stated that, *people can change, people can change, anybody for me I know can change if you give her knowledge*.

> *Automatically, when you have the knowledge, it will change the attitude, when you have been believing in myths and misconceptions, when you have the knowledge, you cannot believe in them again, that is what I think. (Vincent, CHW)*

Vincent highlighted in the above quote that educating women is able to help change the attitude of women by addressing fear and negative beliefs including myths and misconceptions associated with breast cancer.

Therefore, breast cancer education does not only provide knowledge about breast cancer but also dispel myths and misconceptions by letting everyone know that *breast cancer is for everybody* (Alice, CHW). The CHWs were also of the opinion that breast cancer education can help to demystify breast cancer such that community will come to understand that '*having breast cancer is not a taboo. It is not a sin, but it is a disease similar to any other disease' [Stanley, CHW].* Lillian, an NGO representative gave an example of how CHWs provided true information about HIV/AIDs thereby dispelling any myths and misconceptions relating to the disease.

> *If we get the knowledge about it [breast cancer] we can tell them the truth about cancer because do you remember about AIDs? People also thought that AIDs means the person is bewitched but going on talking about it, telling them if you do this you can prevent it. So, if we get the knowledge, we the CHWs it's very easy for us to pass the knowledge to them, tell them the truth that it's not like that. (Lillian, NGO 5 representative)*

Knowledgeable health workers

The CHWs as well as key informants identified having PHC workers who are knowledgeable about breast cancer detection as an important resource for delivering breast cancer detection 'on the ground'. A crucial prerequisite for having knowledgeable health workers as identified from the qualitative study involves capacity building of the health workers.

> *First of all, I must say the first thing we need to do is to improve the capacity of the health workers because these health workers, they are most of them I must say they are not aware, they don't even know the simplest examination. They don't know maybe you tell a mother put up your arms and see maybe the breast is okay at the first level. So, first of all, the health workers themselves they are not informed. They need to be educated so that they can be able to screen at the first phase not just wait when it is too late... Also, the VHTs, when they are capacitated, when they are given some small funding, they can be able to bring up masses but the challenge we get is sometimes you want these VHTs to bring you so many mothers to one place but they also, even themselves they don't have like transport to move. (Agnes, district health team representative)*

As Felix added in the quote below, training for health workers should not only include specialised skills but also cover soft skills like counselling to provide effective interaction with the service user.

> *And the health workers, they are also taken through counselling skills and how they can at least help the patients to understand what they are going through. You know when it comes to what goes around, what they hear from fellow community members, it scares them even to go to the health facilities. That's why sometimes they run to spiritual leaders and pastors. This country is full of churches, so they say before they tell me this is a big problem, let me go and pray until this problem disappears. Yet, it is just growing and by the time they come, it is worse. (Felix, HC III representative)*

However, a CHW explained that it is insufficient to have the knowledge and that the health centres staff should be able to put their knowledge into practice.

> *`The health workers must be taken for training where they can learn how breast cancer can be checked, prevented and they learn all the stages. And then when they come back, they put those things in practice not to sleep on it. So, when they've put those things in practice, we can now create awareness. (Alice, CHW)*

In terms of training, the CHWs especially emphasised the need for training for themselves to enable them to pass 'true knowledge' to their community members. According to Constance in the quote below, training provides the CHWs with the *truth* about breast cancer. It is only after the CHWs have this truth that they are then able to pass across the true knowledge to community members.

> *For me, I think we have to be trained first and we come to know where they [the women] are coming from. Then, when we are trained, we will be able to train or to teach the women in the community the truth about it. But if we don't have any truth about it, it will be difficult to go and teach people in the communities…In fact, what we need from you or any other organisation- we have to be trained about it [breast cancer]. We have to be having a big knowledge about that to help us give true knowledge to the community, we have to be trained. (Constance, CHW)*

Motivation packages

Capacity building also involves providing motivation packages such as incentives for CHWs and mentorship opportunities for the health centre staff. The incentives identified include job aids like posters, umbrellas, gumboots, personalised t-shirts with appropriate breast health message and regular stipends.

> *We need the posters. The posters are very needed because you know in health you cannot cram everything such that it helps us to be remembering what I am going to tell you. And for the training, transport refund since the training will be done in the community, the t-shirts to go out in when we are in the field having that message of breast cancer on the t-shirt. (Lillian, NGO 5 representative)*

Alex, another CHW also highlighted that the CHWs *need some boots for when it is raining, we need some umbrellas, we need some jackets sort of*. Lastly, in relation to motivation packages, the study identified the need for mentorships for PHC staff.

> *Then the other thing will be at least the health facility, health workers, they need that motivation, we motivate them through mentorship through at least giving those breaks and helping them with the transport when they go for outreach and what, something like that, it would do this. (Felix, HC III representative)*

Community-based multi-media platforms

The study findings established that breast cancer awareness can be provided using different community-based multimedia resources. The multimedia resources identified comprise of a mix of print, audio and visual resources already existing and used to pass information regarding other health issues and include infographics, flip charts, mobile public radios. These resources can be targeted at health care providers or community members.

The study highlighted the use of simple infographic resources such as charts or posters designed in the local language as a low cost and effective way of passing across breast health information. According to Kevin (HC II representative) the infographics can be put up at different public places in the community.

> *Still, in the community there is a way of communicating maybe we can use those charts and we pin them in public spaces when the information is summarised most especially in the language they can understand. Some can get time out and they read because majority now they know how to read, they can read and get to know. (Kevin,* HC II representative*)*

Some of the CHWs and key informants identified local community radios as useful public platforms to create awareness around breast cancer. The description of these local community radios was similar to megaphones and CHWs expressed that these platforms are valuable because they can cover more than one village at a time.

If you go to the village, we have these local local radios we just call them radios- this local local public system. So, if there is that programme of like going there and informing people via that thing at least someone can just be informed. Because if you don't have a TV or a radio or a phone but you can't stop your ears from hearing from the local ones. At least if there is that programme of also using the public radios. (Anita, CHW)

Agnes, a key informant further identified the use of a film van which is provided by the Ministry of Health. The film van also has the ability to pass information across many villages as it is mobile. In addition, she indicated that the film van could be used as a public address system or video display system at public places such as markets.

The film van- it is like we get it once in a while when we have campaigns, maybe immunisation campaigns. We request for it from the Ministry, they send it with a driver and then also we provide somebody at the facility, we look for a health worker to move with the film van. So, as the film van goes, the health worker can record some information, or the health worker goes with the microphone speaking as the film van moves around the different communities like the trading centres. Even when it reaches the trading centres or small towns, it has like a video show. Whatever information that you want the public to view, you put it and people get to see and if there are any questions, you give them a chance and they ask and then you proceed to another place. But as I said they are only at the Ministry, as a district, we don't have a film van, but you can only request for it and they send it to you with the driver. And you have to provide funding for the driver and also the fuel for the film van. (Agnes, district health team representative)

Lastly, one of the CHWs (Vincent) suggested that since some health centres have TVs, video shows on breast cancer can be put on display so that as visitors wait to see the health provider, they can listen to and watch these videos.

Video shows, they can really pass the information because some facilities, they have TVs, but they don't have the videos. So, they can be provided with videos, it will really be good. (Vincent, CHW)

Policy Requirements

All the key informants and some CHWs identified the need for a national cancer policy and breast cancer detection guidelines as well as prioritisation of preventative approach as practical solutions. In relation to having breast cancer guidelines in place, the key informants and CHWs agreed that there is a need for the government to put in place a cancer policy to guide decentralisation of breast cancer detection services to the PHC centres.

> *If the government supports it [breast cancer] and puts in a policy that every government facility has to be doing it [breast cancer detection], I think it will work. Because for us on the ground, the VHTs, we are just there for the government. Whatever programme comes, we can render to the community. (Constance, CHW)*

Constance's opinion about having a policy to guide the provision of breast cancer detection services at the PHC centres was corroborated by Sharon, an NGO representative in the quote below.

> *They [the government] need to develop the policies and screening guidelines so that these people [health workers] have a kind of national direction, they have some guidelines in place, and they can have some sort of supervision and monitoring. (Sharon, NGO 4 representative)*

Sharon's quote also suggests that without a policy, it would be difficult to supervise or monitor efforts geared towards breast cancer detection at the PHC level. In addition to having a breast cancer policy in place, key informants called for a high-level commitment to drive breast cancer detection activities at the community level through prioritisation of health education and a preventative approach and not just investing in breast cancer treatment.

> *If health education was given a priority and we sensitise the people out there, most diseases can be prevented. But it is like they are putting more emphasis on treatment which is actually not true… maybe we need to show that there is really a need you know like we show that you people see the non-communicable diseases are taking over, what do we do? (Agnes, district health team representative)*

Agnes, in the quote above suggests that there might be a *need to show* why breast cancer should be prioritised. However, according to Sharon, there is changing political climate in Uganda which is timely to gather the required attention at a high-level as cancer and other NCDs are now affecting top-level national government officials.

> *And I think the beauty about is that the political climate is generally changing, you now have to pay attention to NCDs. Because in a country like Uganda, HIV is there but it's no longer as much as it used to be and now, they are realising that NCDs are taking over and with this government where government officials are now dying, if it's not cancer, it's cardiac arrest, its heart diseases so people are really waking up. (Sharon, NGO 4 representative)*

Funding

Lastly, the study revealed that delivering breast cancer detection 'on the ground' depends on funding. All the participants indicated that *they need money* to put in place any breast cancer detection programme. However, the funding requirements indicated were not related to setting up new infrastructure but mostly associated with providing multi-media resources, consumables related to capacity building PHC workers, and facilitating the functions of support personnel. For instance, funds are required to train the CHWs and other stakeholders who might be involved in the delivery of breast cancer detection services. Specifically, CHWs are usually provided with training allowance and refreshments during training programmes. So, funds are required to cover these as indicated in Caroline's quote:

> *There's also the need for money because you cannot train them [CHWs] without at least giving them a small token because some of these VHTs live very far at least they need some little transport and even those who are going to facilitate them, they need some small allowances. (Caroline, HC IV representative)*

In the quote below, Agnes also highlighted that funds are also required for multi-media platforms like the film van and megaphones which are used to deliver community outreach services for early breast cancer detection.

Then the funds that you may need may be for things like the film van, those are also small funds and maybe funds for the officers moving with the film van. And as the VHTs are trained, normally we give them some small transport allowance and sometimes we give them some food because it is like a full-day training, something of such. Maybe the other little fund that may be needed is maybe for mobilisation because I will tell the VHTs to mobilise for me people. Yet the VHTs will move from house to house calling the mothers but sometimes there's what we call megaphones. When we want something to be heard by many people, we use some megaphones, so we put somebody around with the megaphones and this person move to call everybody. You people, this day there's this and that and people turn up in big numbers. Sometimes, we also do some radio announcements something of the sort, so some little funding for mobilisation. (Agnes, district health team representative)

5.3 Discussion of Qualitative Findings I

5.3.1 Delivering breast cancer detection 'on the ground'

The first theme from this study established that breast cancer detection services should be delivered 'on the ground', at the town council level. This concept of delivering breast cancer detection services 'on the ground' level aligns with a PHC approach. It also connotes a population-based approach which is focused on improving breast cancer detection measures at a general population level and not restricted to the at risk, the symptomatic or the sick population as indicated from the study findings. In this sense, the first theme can thus be surmised as improving access to breast cancer detection for all, the emphasis being on 'for all' which is an underpinning principle of the PHC concept (Sanders et al. 2019; WHO 1978). On the other hand, the reference to bringing breast cancer detection services to the ground level suggests a desire by the study participants for breast cancer services to be decentralised from a national to community level. This is most likely because the existing and widely known government-funded breast cancer detection services are predominantly available at the national cancer referral hospital in the capital city, Kampala. Therefore, delivering breast cancer detection services 'on the ground' in this context basically implies decentralising

aspects of breast cancer detection from the national referral hospital level to the community level. This concept of decentralisation has been identified in the Ugandan *National Health Policy II* as a way of strengthening the health system (Ministry of Health 2010a) by transferring the responsibility for health care delivery from the central government to the community level (Ssali 2018). Specifically, Sayed et al. (2019) highlighted decentralisation as a way of increasing breast cancer awareness at the sub-county level in Kenya. Although Uganda practices a decentralised health care system (Henriksson et al. 2019; Ministry of Health 2010a), breast cancer services have not yet been decentralised. However, this suggestion has been implemented in Peru, where a community-based breast health programme was put in place to promote breast cancer awareness and capacity building of PHC workers (Duggan et al. 2017). In the case of Kajjansi town council, two interventions were identified from the study on how best breast cancer detection services can be delivered at the community level through leveraging on the existing PHC system and using community outreach.

5.3.2 Leveraging on the existing primary health care system

Delivering breast cancer detection at the PHC centres does not necessarily require setting up a new system as the study findings show that the existing PHC system can be leveraged through integrated PHC service delivery. Existing studies (Reeler et al. 2009; Varghese et al. 2019) have argued for the integration of breast cancer and other NCDs services into existing health programmes as a sustainable and cost-effective model of health service delivery. An integrated approach to providing breast cancer detection services aligns with the principle of the Alma-Ata Declaration (WHO 1978) and Astana Declaration (WHO 2018a) which called for comprehensive rather than selective health care. As evident from the study findings, breast cancer detection services can be integrated with health services that specifically target women such as breastfeeding, immunisation, ante-natal, post-natal, family planning and HIV services. These health services have been previously identified for providing opportunistic breast cancer detection in Nigeria (Ishola and Omole 2016). A systematic review by Duffy et al. (2017) also provides evidence on the integration of NCDs with HIV services in Kenya, Nigeria, Uganda, Zambia and Tanzania. A potential challenge of integrated PHC service delivery is the strain on existing human resources which was highlighted during the interview with the HC IV representative, Caroline. In agreement with Caroline's response that this

challenge could be addressed through task allocation, a knowledge summary document produced by a coalition of international cancer control agencies (The United States National Cancer Institute, Breast Health Global Initiative and Union for International Cancer Control) also cautioned that while integration with women health services provides synergistic opportunities, there is a need for effective human resource allocations to avoid additional strain on the PHC system (Anderson et al. 2017). Therefore, there is a need to ensure that integrated strategies optimise the existing PHC system without putting a strain on the resources, both human and financial.

Conversely, the study showed that the existing PHC system could be leveraged by learning from the practice of having designated day for specific health issues. It was evident that the PHC system in Kajjansi town council had designated days for some health issues, including ante-natal and HIV services. This practice is similar across different parts of Africa, including South Africa (Ebonwu et al. 2018) and Nigeria (Peters et al. 2014). Although the effectiveness of a designated clinic day is understudied, there is an indication that going to the health centre on designated days does not address accessibility challenges as demonstrated by the increasing research on the use of mobile clinics to enhance uptake of antenatal services (Edmond et al. 2020; Peters et al. 2014; Phillips et al. 2017). However, the use of scheduled breast cancer clinic days is an emerging area of practice for breast cancer control in SSA and was recently piloted in a neighbouring country, Rwanda (Pace et al. 2018). Pace et al.'s (2018) pilot study shows that having designated breast cancer clinics has the potential to serve the communities within the coverage area of each of the health centres. Therefore, it can be deduced that the delivery of breast cancer detection services whether through integration with existing health services or establishment of scheduled breast cancer clinic days has the potential to strengthen the PHC system with minimal resources. However, this still leaves a huge gap of 'healthy' women who have no noticeable reasons to visit the health centres. Addressing this gap, therefore, calls for an alternative of organising outreach to meet those women within their communities.

5.3.3 Community outreach

Beyond providing early breast cancer detection services at the health centres, the study established the importance of taking these services into the community through outreach to enhance accessibility to the wider population. The concept of community outreach as interpreted from the qualitative study findings is somewhat different to that described from the situation analysis which revealed that organisations who had supported with breast cancer detection programmes did so by organising outreach at the health centres. In this case, community outreach for breast cancer detection is used to depict community-based programmes only, that is taking health service delivery into the field as described by Roodenbeke et al. (2011). Importantly, community outreach was identified as a way of addressing distance and poverty challenges in relation to the early detection of breast cancer. The use of outreach in accessing health service users especially in remote settings prone to distance challenges is well documented (Edmond et al. 2020; Roodenbeke et al. 2011; Partapuri, Steinglass and Sequeira 2012). Particularly, the use of community outreach has been highlighted as an effective strategy to promote breast cancer screening as part of the United States National Breast and Cervical Cancer Early Detection Programme (Levano et al. 2014). Levano et al.'s (2014) recommendation around outreach strategies was that community outreach for early breast cancer detection should be community-based, informed by community needs and culturally appropriate. Taking the services to the community level settings presents a more naturalistic and population-based approach to improving breast cancer detection among women. It is naturalistic as outreach target women in their natural settings, for instance, the study findings suggested that women can be reached at marketplaces. Also, community outreach align with a population-based approach as it can be targeted at a specific population, whether healthy or sick or both (Buist et al. 2017; Roodenbeke et al. 2011). This population-based approach is important as women who perceive themselves as healthy may not see a reason to attend breast cancer detection clinics at the health centres.

The study further indicated that community outreach programmes are best delivered by people who are positioned as insiders within the community. This is an important point as there have been critiques around the use of outsiders in delivering community-based

programmes especially due to their paternalistic approach which inhibits community participation (Botes and Van Rensburg 2000) and detachment from the community's contextual realities (Staples 2016). Similar to findings from this study, Staples (2016) also showed that the use of outsiders in community organisation might breed distrust among community members. Therefore, the positionality of those involved in delivering community-based programmes is an important factor to consider. It is recommended that PHC workers who are close to the community, the CHWs are engaged in the delivery of an early breast cancer detection programme. That said, the insider-outsider dynamics have also been discussed in relation to CHWs positionality (Grant et al. 2017; Mlotshwa et al. 2015; Perry et al. 2019). For example, a recent study exploring the roles of CHWs in Uganda (Perry, et al. 2019) and South Africa (Mlotshwa et al. 2015) revealed that CHWs navigate through multiple roles as insiders, outsiders and intermediaries. These authors conceptualised CHWs as insiders based on their proximity to the community. The positionality of CHWs as insiders and their value in promoting breast cancer detection has been previously recognised by past studies in Australia (Javanparast et al. 2018). According to Javanparast et al. (2018), CHWs have 'lived experience' (p. 948) of the contextual realities of the communities in which they reside. Thus, their experiential knowledge and positionality as insiders have the potential to increase trust and community acceptability of the CHWs (Grant et al. 2017; Javanparast et al. 2018). However, the positionality of CHWs as insiders does not always breed trust as shown in section 6.9.3, which discusses the specific roles of CHWs in promoting early detection of breast cancer. Understanding the positionality of the different health workers in delivering community outreach programmes is important as it has implications for acceptability and eventual uptake of such programmes.

5.3.4 Resources required for early breast cancer detection

Similar to findings from this study, it has been previously established that community-wide breast health education is essential for creating awareness as part of early detection of breast cancer (Finkel 2018; Sivaram et al. 2014). From the study findings, it was evident that knowledge of breast cancer is a key resource to promote early detection of the disease. Although knowledge is not often constructed as a resource, it has been conceptualised as a form of resource in different disciplines like management (Nag and Gioia 2012), regional

development (Scherer and Schnell 2008) and mental health care (Baillergeau and Duyvendak 2016). These evidences agree with the qualitative findings that knowledge is indeed considered as a resource. As further established from the qualitative findings, breast health education can address the individual level challenges faced by women such as fear, dispel myths and misconceptions and curb community attitudes around stigmatisation as was the case with HIV/AIDs in Uganda. A wealth of evidence exists, which shows how knowledge was crucial in addressing the HIV epidemic in Uganda through behaviour change. For instance, the Joint United Nations Programme on HIV/AIDS (UNAIDS) case study entitled *Knowledge is power: Voluntary HIV counselling and testing in Uganda* (UNAIDS 1999) and peer-reviewed articles (Bessinger, Katende and Gupta 2004; Kwagonza, et al. 2020). The findings from this study is also consistent with other studies (Agbokey et al. 2019; Hall, Pfriemer and Wimberley 2007) which identified knowledge as a catalyst to increase health-seeking behaviour. An experimental study conducted by Hall, Pfriemer and Wimberley (2007) among Hispanic women in the United States revealed that breast education programmes significantly increased the knowledge levels of women and motivated them to utilise existing breast screening services. Mckenzie et al. (2018b) further drew a direct correlation between education and stage of breast cancer diagnosis, establishing that women with greater knowledge of breast cancer were usually diagnosed earlier at stages I and II. Therefore, knowledge is a key resource to catalyse behaviour changes in promoting early breast cancer detection.

The CHWs in this study also associated breast health education with providing 'the truth' about breast cancer. This suggests "clear, articulate and correct information about breast cancer" (El Saghir et al. 2011, p. s5) which is an urgent need for cancer control in LICs (El Saghir et al. 2011). Also, this concept of providing the 'the truth' about breast cancer can also mean providing comprehensive information such as knowledge around breast cancer signs and symptoms as indicated in the study findings. Comprehensive knowledge including messages around signs and symptoms, risk factors and where and when to seek medical help is essential for empowering women to detect breast cancer early (WHO 2017a). Passing across the right awareness messaging is not only important for individual empowerment but for accurate global breast cancer campaign. For example, although the presence of lumps has been the

most common sign of breast cancer or other breast diseases, recent studies have shown that inflammatory breast cancer, an aggressive type of breast cancer which is common among African women is not usually associated with the presence of lumps (Robertson et al. 2010). Hence breast cancer awareness messages that highlight lumps may be misleading in this case. Also, due to the epidemiology of breast cancer, it usually does not present with pain at the onset, so, women need to be aware not to watch out for pain as a motivation to seek health care. Perhaps, it is for this reason that breast cancer awareness messages generally focus on changes in breast whether shape, size or consistency as an approach to detecting breast cancer.

In recent years, there has been an increase in national efforts around breast cancer awareness in Uganda, as evidenced through social media campaigns and publicity. However, these efforts are neither grounded nor guided by any breast cancer policy framework or guideline. This is because Uganda still lacks a national cancer policy to guide requirement of breast cancer services at the PHC centres as revealed from the situation analysis. The implication of this lack of a policy is that national efforts are neither sustained nor replicated at the community levels. Thus, another key resource identified from the study finding is the need for a breast cancer policy and guideline, specifically one which favours a preventative approach. The requirement to have an NCCP is a requirement from the WHO to its member states (WHO 2002). The WHO specifically recognises that "A well-conceived NCCP is the most effective instrument that will bridge the existing gap between knowledge and practice" (WHO African Region 2012, p. 10) for cancer control. However, existing evidence suggests that the development of any policy is informed by evidence obtained through scientific research (Abimbola, Baatiema and Bigdeli 2019; WHO African Region 2012). This is problematic for Uganda as there is insufficient evidence to inform cancer development policy in the country. As this study further indicated, such evidence is necessary to drive political commitment. Although this study findings have the potential to contribute to such evidence especially in the area of early detection strategies, there is still a need for ongoing research to expand the existing evidence of breast cancer incidence and prevalence in the country in order to garner political commitment.

Having a breast cancer policy in place is a great step towards progress, however, adequate human resource capacity is required for successful implementation (Anderson et al. 2017). The study also highlighted the need for knowledgeable PHC workers through capacity building. This is consistent with the WHO (2017a) recommendation and findings from other studies (Sankaranarayanan, Ramadas and Qiao 2013). This study findings particularly indicated that being knowledgeable enables the health worker to be proactive by providing routine breast examination and not waiting until a woman becomes symptomatic. Although the government's current strategy for capacity building as part of its NCDs control targets HC IV as the lowest level of provision (Ministry of Health 2015a), this study shows that capacity building can be practically targeted at different cadres of PHC workers. Bridges et al. (2011) identified capacity building as a key strategy in their multi-region studies on comprehensive breast cancer control strategies. An aspect of Bridges et al. (2011) findings is similar to this study in the sense that capacity building called for targeted training of different cadres of health workers within the PHC system to promote effectiveness. Targeted training of CHWs and nurses has been implemented in Rwanda a neighbouring East African country (Pace et al. 2018). An assessment of the training programme in Pace et al.'s (2018) study revealed a substantial increase in CHWs knowledge and nurses' skills immediately after the training and 3 months post training. The CHWs in Pace et al.'s (2018) study were affiliated with health centres to receive breast cancer detection training from nurses. The PHC workers training intervention was complemented by the establishment of weekly breast cancer clinics (Pace et al. 2018) which was also another solution highlighted from this study.

The study findings further showed that capacity building goes beyond the training of PHC workers. According to the WHO, capacity building is the "development of knowledge, skills, commitment, structures, systems and leadership to enable effective health promotion" (Smith, Tang and Nutbeam 2006, p. 341). This definition indicates the need for resources to enhance commitment. Examples of such resources as identified from the qualitative data findings are mentorship for PHC staff and incentives for CHWs. It is problematic to train CHWs without providing incentives for them, especially in the cases of volunteer CHWs such as those in Uganda. A study conducted on motivating factors for CHWs in Ethiopia identified refreshers training and provision of certificates as the two main non-financial incentives to motivate

CHWs (Haile, Yemane and Gebreslassie 2014). There is also an indication from existing literature that non-financial incentives are preferred by CHWs (Haile, Yemane and Gebreslassie 2014). In relation to mentorship, Pace et al. (2018) have shown through their breast cancer detection pilot programme in Rwanda that having an on-site mentorship has the potential to sustain the knowledge and skills of health workers. Therefore, a capacity building intervention to promote breast cancer detection should not only focus on building the knowledge and skills of PHC workers but also provide resources to sustain them.

Lastly, the qualitative data suggest that delivering breast cancer detection 'on the ground' requires funding. It is evident that the two interventions highlighted (leveraging on existing PHC system and community outreach) as well as other resources required depend on funding availability. This means that funding is integral to promote the early detection of breast cancer and its significance cannot be overemphasised. As established in the situation analysis, the study focus is on government funded PHC centres, so the discussion of funding here focuses on government allocations and donor funding, it does not consider health service user fees. Funding does not only determine the availability but also the quality of PHC services delivery, hence it is also a major prerequisite for achieving the universal health agenda. The WHO (2002) also highlight that the establishment, as well as implementation of the NCCP, relies on funding. As seen from the study findings, although funding is integral, it does not directly lead to PHC strengthening. However, it can facilitate processes or activities required to strengthen the health system. Therefore, it is important to note that availability of funding in itself may not be a problem but how the funds are administered and managed might inhibit the effective delivery of breast cancer detection services at the community level.

Chapter Summary

This chapter provides an overview of the qualitative research findings which are broadly categorised into six main themes. Specifically, this chapter presents and discusses findings from the first theme: delivering breast cancer detection 'on the ground'. This first theme highlights how breast cancer detection services can be made available at a PHC level through leveraging on the existing PHC system and carrying out community outreach. Furthermore, this chapter presents the resources required to promote early breast cancer detection

including knowledge, knowledgeable health care workers, motivation packages, community-based multimedia resources, policy and funding. The next chapter presents and discusses the second theme which focused on the need for a collaborative approach to deliver early breast cancer detection.

CHAPTER SIX

6.0 QUALITATIVE FINDINGS II

In this chapter, I present and discuss findings on the second theme (A 'collaborative approach') that emerged from the qualitative data analysis. Although the qualitative study deliberately set out to understand whether and how women are engaged in PHC service delivery and also to explore the potential roles of CHWs in breast cancer detection, the findings expanded on these by showing that women and CHWs are not the only ones to be engaged. The different stakeholders identified from this study are presented as sub-themes as shown in Figure 6.1:

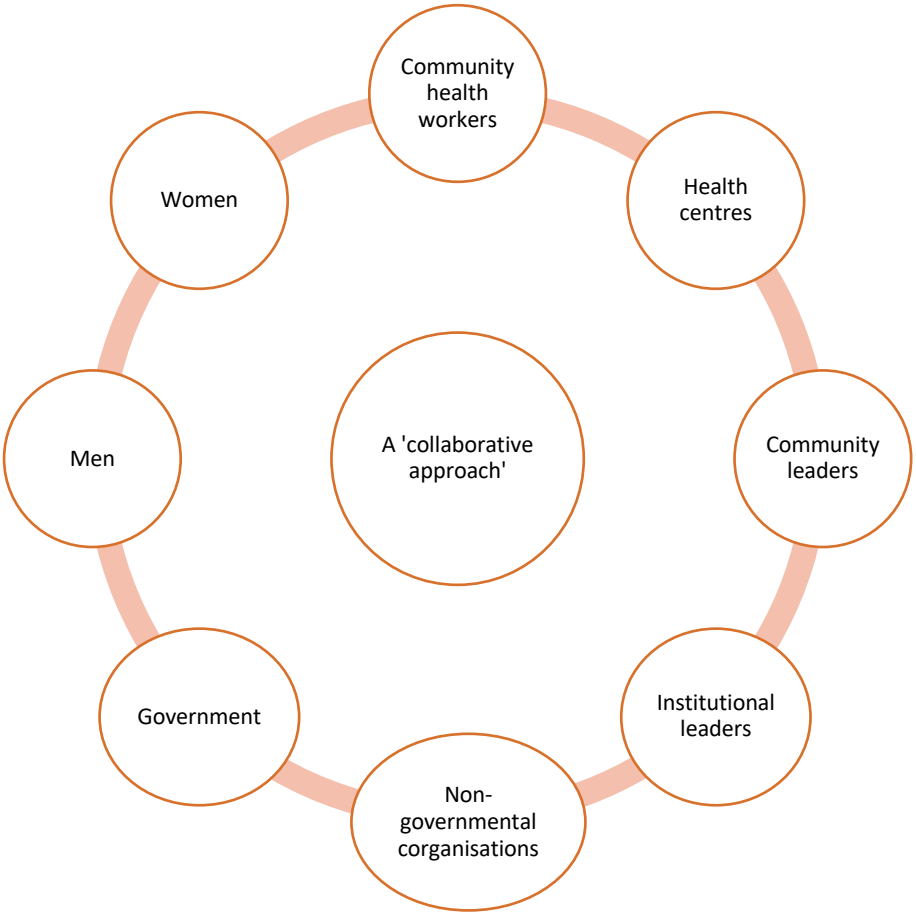

Figure 6.1: Illustration of sub-themes within a 'collaborative approach' theme

The study established that a 'collaborative approach' through engaging with these different stakeholders (shown in Figure 6.1), which Mark (district health team representative) referred to as '*collaborating agents'* is crucial for delivering breast cancer detection 'on the ground'.

> *When it comes to collaborating agents, we need to appreciate that as health educators, we can't work alone. For example, we are bringing the VHTs on board, we are collaborating with them. We also need to bring the development people on board because you realise that when someone has breast cancer, it not only affects her, it also affects the productivity. That's why you come to work with an agricultural officer who is responsible for production in your community. This is to see that the disease is attacked from different corners and that means we are doing a collaborative approach in managing health issues. (Mark,* district health team representative*)*

Mark's reference to *attack[ing] from different corners* implies a collaborative approach that does not only reflect multiple stakeholders but also connotes engaging with stakeholders beyond the health sector such as, engaging with *the development people* from the agricultural sector.

The following sub-sections focus on how the different stakeholders can promote early breast cancer detection.

6.1 Roles of Community Health Workers in Early Breast Cancer Detection

All the study participants established that the CHWs have a crucial role to play in promoting early breast cancer detection because they are the first point of contact, especially for community level breast cancer detection programme.

> *From the community point of view, the first thing will be to involve the CHWs. I don't know in whatever form, whether they are trained or not trained, we can bring them and train them since they are already doing something about health at community level…So, let's work with what we have, sensitise those who are there, teach them and then give*

the opportunity so they can also share with the communities. (Sharon, NGO 4 representative)

As indicated in the quote above, it is practical and reasonable to maximise the potential of the CHWs since they already exist. Specifically, the study established that the key roles of CHWs include breast health education, performing breast examination, community mobilisation, and giving referrals. These roles are succinctly summarised in Vincent's quote below.

Mainly for us as VHTs, our major role there is to give health talks in the community, to show them the needful, why do they need to test early, how they can control themselves, that is our major role and again to mobilise. If for example, the health centres have started the outreach, VHTs must be part to mobilise because they live in the communities so health workers cannot go there without VHTs so to mobilise to give health talks, those are the major ones. And again, to refer, even referring those whom I can say that they need to be tested; even referral is our role. (Vincent, CHW)

From Vincent's quote, it is evident that CHWs *give health talks* to educate women on breast cancer and the *need to test early, [and] how they can control themselves*. CHWs also show women *the needful*, that is, they can show them how to perform breast examination as a way of detecting breast cancer early. Vincent also revealed that even when the health centres organise community outreach, the health personnel are unable to access the community members without mobilisation support from CHWs *because they live in the communities*. As a result, the CHWs are also well placed to refer a woman to the health centres for a further check-up in case of breast concerns.

The most prominent role of CHWs identified was creating awareness at the community level through breast health education. In addition to educating women as presented above, the quote from Bianca below shows that CHWs are also able to provide information to women around scheduled breast cancer clinic days.

For that one, they can talk to us VHTs and we can talk to the mothers and if they put that on for example on Friday, we are going to screen for cancer then we have to know

that on that facility every Friday they screen so that everyone knows and when we go to the communities, we tell them that on that facility they do this and this on Friday. (Bianca, CHW)

Breast health education could also include CHWs teaching women how to perform BSE as indicated by Lillian, a key informant that: *the idea is that we VHTs can tell them and at least teach them how to assess themselves, but we can [also] refer*. CHWs are able to provide breast education because they are *foot soldiers* which imply that they *have that greater access* [Stanley, CHW] to the community and *are positioned to share their knowledge* [Mark, district health team representative].

First and foremost, when it comes to awareness, our foot soldiers in the community that is the village health team, I'm very certain that if these people [CHWs] are empowered because I said that they are our foot soldiers on the ground, they will be able to recognise these critical signs and symptoms in these mothers. They will create awareness through their meetings and gatherings, they are positioned to share their knowledge. (Mark, district health team *representative)*

Empowering the CHWs as alluded by Mark's quote indicates that an important precursor to the CHWs' abilities to deliver their roles is capacity building as presented in chapter five (section 5.3.4).

CHWs were further identified as an integral platform to drive the community outreach. The importance of CHWs in driving community outreach was buttressed by a key informant who stated that:

So, the main goal of the VHTs being created was to reach every household with health services having had issues of poor terrain in some districts, issues of long distances to health centres. The health centres cannot reach every household so we thought it will be good for VHTs to be our representative or our ambassadors, champions so that we are able to reach every household. (Edna, Ministry of Health representative)

An important finding from this study was a general perception from interviewing the CHWs that the health and wellbeing of their community members is their responsibility. The CHWs

themselves recognised that they are in the best position to advocate for their communities and communicate the prevailing health needs to their superiors. The roles of CHWs as advocates was strongly evident through their feedbacks after responding to the interview questions. Both the female and male CHWs were interested in the outcomes of this study and they asked about what to expect in terms of helping and supporting the women in their communities to detect breast cancer early.

> *In fact, thank you very much, you've talked about a good thing which I would like to be taken important. I'm a female therefore I'm begging if there is any help there you can help to reach Uganda. I've already told you that we are ignorant about that [breast cancer]. What I am begging- we need your help, if you are having any, we need your help, we have to help the women there in the communities to teach and to treat. For me, I know we have the victims out there, but we don't know. What can you do to help us? We don't need money; money can't be enough but about health what are we hoping from you? (Constance, CHW)*

In the quote above, Constance did not only acknowledge the importance of promoting breast cancer detection which she refers to as *a good thing*, but she can also be seen *begging* on behalf of *women* in her community suggesting the urgency for action to address the widespread ignorance around breast cancer detection. As an advocate, Constance acts as a mouthpiece for women and even *victims* to solicit for help. Her role as a mouthpiece here is similar to what Evelyn (NGO representative) refers to as *speak[ing] for the voiceless* which also involves communicating the health needs of the community to higher level stakeholders like the health centre managers.

> *What they [CHWs] can do is advocacy. Advocacy basically, you speak for the voiceless. You go and talk to the in-charges and leaders, you tell them what is happening in the villages, you speak for the people. (Evelyn, NGO 1 representative)*

Community Health Workers as the platform for engaging with women

The study further revealed that CHWs are able to provide all these roles as they are the core platform for engaging with women. This is because the CHWS *get to the mothers more than*

any other person [Agnes, district health team *representative].* The study participants drew on existing methods used to engage women on other health issues. I have broadly categorised these engagement methods into collective and one-on-one engagements. These two engagement methods are not presented as either or as the study findings indicated that either of them can be appropriate. With regards to engaging women collectively for breast cancer detection, suggested methods include through existing settings or groups such as community associations. Some of the participants were of the opinion that collective engagement is easier than individual engagement as intimated by a CHW:

> *The issue is to make sure we mobilise them [women] in groups because it is not easy to reach them one by one. Mostly here in our community, the women have their groups where they gather together even for saving. So, that's the easiest way we can use to reach them. (Steve, CHW)*

In some cases where women are engaged in groups, the CHWs clarified that they still offer an opportunity for one on one meetings for women who may have private questions or who are not comfortable to ask questions about their breasts during group engagements.

> *When you end up your [group engagement] session like for example, when I go for the programme to talk about cancer, when I'm ending my session, I can tell them to ask anything they want. After that, if that doesn't work, I get my bench and I sit around, and I tell them if there is someone who has a special need, they can come to me and we talk from there. (Vincent, CHW)*

The study participants also expressed that women can be engaged through door to door home visiting. According to Beatrice (CHW), door to door engagement will help get the information regarding breast cancer detection especially to people who do not participate in group meetings.

> *We pass the message through door-to-door…There is no any other means because these people sometimes they don't want to gather because they are doing their own work, but this message can be passed when we go door to door, we talk house to house, that's how they will know. (Beatrice, CHW)*

6.2 Roles of the Primary Health Care Centres in Early Breast Cancer Detection

At a general level, the study established that the PHC staff are responsible for training the CHWs. The study also identified specific roles of the different tiers of health centres within the PHC system in promoting breast cancer detection.

The study participants likened the role of health centre II in promoting early breast cancer detection to those of the CHWs particularly increasing community awareness of breast cancer and referring women with breast concerns to health centres III or IV.

> *I think the health centre II which are at parish level should be able to at least put banners and posters and just continually say well breast cancer can be prevented or detected. They can have those translated so that everyone in the village can read it. So, they can try to change behaviour through CHC which is communication for health change. (Caleb, NGO 2 representative)*

For health centre III, the identified role in relation to breast cancer detection was also around providing breast health education through posters and leaflets. At this level, it is also expected that a trained health worker will be able to *differentiate between what is benign and what is cancerous and at that point they can probably refer you upwards* [Caleb, *NGO 2 representative*].

> *Mark: Maybe if such screening can be done at health centre II and IV then*
>
> *Int: When you say screening what do you mean?*
>
> *Mark: Screening- a mother can be positioned to tell the signs and symptoms and see that they are actually screening them, examining them so that if they have any cancer cells, it's detected at that stage and saving that life.*
>
> *Int: So, the health workers creating awareness and also carrying out examination on the woman?*
>
> *Mark: Absolutely.*

For health centre III, the identified role in relation to breast cancer detection was around providing breast health education, teaching women about BSE and performing CBE as indicated by Mark [district health team representative] in the above quote.

In the case of health centre IV, in addition to providing services highlighted for health centres II and III, the study findings revealed going beyond detection. It was indicated that the health centres IV have medical officers who can perform surgical procedures to remove breast lumps which are then further sent to Mulago for pathological examinations. So, only women with confirmed breast cancer cases are referred to the national referral hospitals for treatment. However, it was reported that Kajjansi health centre IV lacked a medical officer at the time of this study.

> *What we can do is at least the health centres IV, if we say the health centre IV of which there are seven in total [in Wakiso district]. If you say maybe the centres IV, if those services are there, that means it will reduce the workload at Mulago. Because if a mother knows that if I go to Kajjansi, I will get breast cancer service, if she knows if I go to Ndejje [another HC IV in the district] then in that case they will be able to really do some of those simple simple things. Those simple labs, they can do the cutting and removing the tissue but the testing, they have to send it to Mulago. Though, Kajjansi doesn't have a medical officer at the moment, they are able to, they are skilled enough to do that examination of the breast and if there's a lump, they can cut off the tissue and send it for biopsy. At that level, the medical officer can do that. (Agnes,* district health team *representative)*

As Agnes explained in the quote above, health centres IV are able to do *some simple simple things* like laboratory tests and surgical procedures which go beyond mere detection towards diagnosis of breast cancer. In other words, the health centres IV have the capacity and competence to even go beyond detection but more around breast cancer diagnosis.

6.3 Roles of Community Leaders in Early Breast Cancer Detection

The study further established the need to engage with community leaders such as culture leaders, religious leaders and local political leaders in the delivery of early breast cancer detection services at the community level.

> *Maybe another category of people that you can sensitise so that they spread the work for you in addition to the VHTs are these religious people. Sometimes I've used them and the culture leaders, sometimes I've used them like in the last 2 weeks I was doing sensitisation on Ebola and I must say the first people I trained were the VHTs, I also oriented the religious leaders, the culture leaders and these are the people who move to the people. Because every time there's a village meeting, for example, these are people who are going to say you people we've learnt abcd, it is on the increase, let's do abcd… Like here in Uganda we got like the Kabarka. The Kabarka is like the culture king of Buganda kingdom and the wife if like you got such [breast cancer] runs you go through her and you tell her maybe we want to do breast cancer awareness. So, if now it is brought by such a big person when the mothers are called upon, they turn up in big numbers. But at a district level when you say you are calling mothers may be to participate in the run, somehow somewhere it may not be easy for you but when you go through those big people, it becomes very easy for you. (Agnes, district health team representative)*

Agnes specified that where applicable, a *big person* like the wife of community leaders, for instance, the *Kabarka*, culture leader of Buganda kingdom can provide ease of access to women during a breast cancer campaign as she has done with fistula awareness. The use of 'big' here connotes a position of influence and respect. Just like the CHWs, Agnes also points out how community leaders are key points of contact for community members and they are well placed to mobilise women during community outreach.

It is evident from the quote below that Steve who is a CHW regards the community leaders as being more influential in mobilising women than the CHWs. In this regard, the community leaders can be also likened to gatekeepers who provide access to community members due to their *big* status.

I think we have big people more than us for example the area councillors, the area chairpersons, parish chairpersons. They are good in mobilising, if they call people for a seminar or for a workshop they can respond. (Steve, CHW)

In order to effectively perform this gatekeeping role, Vincent (CHW) explains that there is a need to first get the community leaders to *buy into* the breast cancer detection programme. Getting the community leaders' buy-in involves a process of dialogue and sensitisation so that they are also educated about breast cancer. Only then, are they able to mobilise and motivate women to participate in breast cancer detection programme.

We can first have a dialogue or meeting with local leaders, and we show them the need to educate the community about cancer so at the end of the day, these local leaders and religious leaders, they buy into that issue [breast cancer]. When they buy into it at the end of the day, they will be able to mobilise with us to make them [women] know the need to be educated about cancer … When we get them on board and we really educate them first so we shall do away with that [misconceptions], we shall really change the attitudes of the community. (Vincent, CHW)

In addition to supporting with mobilisation as previously highlighted, the study showed that community leaders are also able to provide a platform for CHWs to speak at community or religious gatherings.

…the culture leaders, the religious leaders once they are aware which means by the time a VHT wants to stand up in the church and say you people the breast cancer is on a rise, once the leaders are aware that means the VHT will be given priority. Once they are at meetings and these also include the local leaders have been sensitised that means the VHT will stand up and say you people there is this and you will be given an audience. (Agnes, district health team representative)

What can be seen from Agnes's quote is how the community leaders can facilitate the CHWs role of creating breast cancer awareness by giving them the opportunity to speak to women at community gatherings.

6.4 Roles of Institutional Stakeholders in Early Breast Cancer Detection

In addition to engaging with community leaders, the study identified institutional stakeholders from other sectors who can support with promoting breast cancer detection at the community level. These institutional stakeholders constitute traditional healers, education institutions and community development agencies.

The community development agencies represent different non-health specific but wider development sector stakeholders such as community development officers who are responsible for individual and community socioeconomic empowerment.

> *Then the agriculture officers at the sub-county level should also be brought on board because they also reach out to different fields. For example, if they have their own programmes, they can also invite us, and we pass on this information to them. (Mark,* district health team *representative)*

Mark's reference to *different fields* can be interpreted in two ways. First, it connotes how non-health stakeholders such as the agricultural officers are able to provide a platform for other PHC stakeholders to reach a wider audience. Secondly, it connotes fields of service delivery, for instance agricultural fields.

School teachers within the community were also identified as having a key role to play in ensuring intergenerational awareness by creating breast cancer awareness among young girls and youths. For instance, Beatrice (CHW) stated that: *even the teachers they can pass that to young women who have not grown up, the youths in the schools because they are many young women there.*

Lastly, the study findings showed the need to engage and educate the traditional healers. Although the women will be educated, it is important to also engage the traditional healers, sensitise them so that they can advise or signpost the women to the health centres appropriately.

> *The other thing is at least these traditional healers, they also need to be taught…If they can also be put into the system and they are also supported and mentored and told that*

please look here, we have this in the country, and we need to address it. Like how we addressed HIV because HIV was also the same, people used to say I'm bewitched and what until when the witch doctors were also sensitised and sometimes, they reach a point and say please you can also go and do a test on HIV and see what is really happening. (Felix, HC III representative*)*

According to Felix, engaging with these traditional healers is essential to avoid mismanagement of breast cancer which remains a common practice. From Felix's quote above, it is evident that engaging traditional healers and providing them with adequate knowledge has been successful in the management of HIV. Thus, if traditional healers have the right knowledge, they are able to refer women to the health centres as they have done with HIV by asking their clients to *do a test on HIV and see what is really happening.*

6.5 Roles of the Government in Early Breast Cancer Detection

Based on the study findings, I have categorised the government stakeholders into national and sub-national levels. At the national level, the government stakeholders comprise of the Ministry of Health and the Uganda Cancer Institute while the district health team sits at the sub-national level. Generally, participants were of the opinion that putting in place a breast cancer detection programme at the PHC level is the responsibility of the government, hence should be driven from the top.

It has to come from the top like the government, it has to come down on the ground level…At least, the government has to set up the programmes so that these people from the rural areas they can get informed at least in this way of setting up trainings during meetings and what…If they [government] set up like meetings or training to the village level because we the VHTs we can coordinate, and people can come. (Anita, CHW)

Specifically, the key informants were of the opinion that the government's key roles are to lead on and supervise any community-based breast cancer detection programme. So, although such programmes may not be initiated or driven by the government, they should still be delivered under the government's supervision and guidance.

Any community intervention has to be district led so any kind of community initiative, the government will have to buy into the idea, and they have to be willing to own it and dedicate time for supervision and providing any necessary support and make sure it's doing what they think it should be doing. So that's one component, that is getting district buy-in. The second is ensuring that the Ministry is always aware and ideally someone from the Ministry is the champion for testing or implementing this new approach and that will be through the commissioner or the NCDs department. (Mary, NGO 3 representative)

Mary's quote above alludes to the need for funders and NGOs to engage with the government in order to get project buy-in for any breast cancer detection programme. She further recommended having a *champion* in the appropriate unit within the Ministry, that is *the NCDs department* to take the lead on such programmes. However, according to Mary, the government also has to be willing and dedicated to lead on breast cancer detection programmes which have been initiated by an NGO.

6.5.1 Roles of the Ministry of Health

At the national level, the study established that engaging the Ministry of Health is crucial for the success and sustainability of any breast cancer detection programme as one of the key informants commented, *if you are implementing any activity at community level without involving the Ministry of Health then I don't know what you are doing* [Mark, district health team representative]. This is particularly important for externally driven programme as such programme can only have a policy influence if it has been championed by the government.

The Ministry of Health was further identified as being responsible for making breast cancer policies or guidelines and approving breast cancer messaging contents. As policymakers, the Ministry of Health provides *national direction* [Sharon, NGO representative] which is then translated into action at community level by the district health team. However, Agnes who is also a key informant indicated that the Ministry of Health does not engage with sub-national and community level actors in the policymaking process. According to her, polices are *only sent to the community level after they have been completely developed by the Ministry of Health.*

Within the Ministry of Health, two departments were identified as having direct roles in the delivery of breast cancer control strategies, the NCDs and health promotion departments. Whereas the NCDs department was identified as being more policy-oriented and restricted to policy development, the health promotion department was identified as the linchpin of all health education and communication activities.

The study also established that the resources to promote breast cancer detection *should come from up* (Sharon, NGO representative). The study specifically showed that the health education department has the *mandate* of supporting project implementers with designing context-appropriate health messages and breast education materials. In other words, it is the responsibility of the Ministry of Health to develop Information, Education and Communication (IEC) resources for breast cancer detection appropriate either for PHC workers or the general community.

> *Then we create materials, we come up with technical messages which have the breast cancer messages- IEC materials which can either contain technical message or basic depending on the target user. (Edna, Ministry of Health representative)*

Additionally, the Ministry of Health serves as the *clearing house* to approve or modify *[m]essages that are audio, visual, print messages, social media messages* [Edna, key informant] to ensure they are context-specific and culturally appropriate.

6.5.2 Roles of the Uganda Cancer Institute

Within the Ministry of Health, the Uganda Cancer Institute was identified as a coordinated and well established semi-autonomous institution comprising of technical experts who actively contribute towards research and development of guidelines and policies for cancer control. The Uganda Cancer Institute has also been the key driver of breast and other cancer interventions at both community and national levels as they were reported to have the technical capacity and infrastructure to support the implementation of cancer control programmes. For example, Sharon highlighted below that they have a *mobile breast screening* van. There is also an expectation as indicated by Sharon that the Government would begin to

play a more active role in cancer control as a result of their collaboration with the Uganda Cancer Institute.

> *I know the cancer institute, for example, had a lot of programmes doing even community screening. Because of the low funding at the Ministry then, most cancer research and prevention activities were happening at the cancer institute and now because they have become semi-autonomous, so they had their own connections, different funders so they were able to do many things. I think they have a van for the mobile breast screening…these are the kinds of experts I invite when we are developing like policies, strategic plans, guidelines. (Sharon, NGO 4 representative)*

6.5.3 Roles of the District Health Team

At the sub-national level, the study revealed that the district health team translates policies set by the Ministry of Health into practical actions, but they are usually unable to carry out this core role effectively due to inadequate financial resource.

> *About the resources, sometimes the government provides but then sometimes the implementing partners they can also come in to give a hand, and then we also have what we call local revenue where a small percentage from the local revenue which is given to implement policies but sometimes the funds that are given are not enough, so you end up seeing that the policy is made but it is not implemented. (Agnes, district health team representative)*

Although Agnes suggested that it is the government's role to provide resources (resources required have been presented in section 5.2.3), however due to financial constraints faced by the national government itself, NGOs are relied upon to sometimes provide these resources. Therefore, this leaves the responsibility of implementing breast cancer programmes with the NGOs as further presented in section 6.6 below.

Asides from translating policies into actions, the study showed that the district health team are perhaps the most critical strategic stakeholders as they act as the middle ground between the national government stakeholders and community level stakeholders. They were identified by key informants as the key focal stakeholders for strengthening the PHC system,

as they *implement [and]…oversee all the health activities in the district…both government and private including the* NGOs [Agnes, district health team representative]. Agnes agreed with Mary's quote presented earlier that *[a]ny community intervention has to be district led*. The district health team is also responsible for facilitating, coordinating and supervising multi-sectoral engagements with different stakeholders at the community level.

> *Okay so at the end of the day, for every partner that works in the district, they are supposed to be known to the district health officer who is in charge of all health work-related in the district, we call him the district health officer. So, the district health officer has a team called the district health team…and they are supposed to hold meetings with those partners, offer them guidance, leadership and technical support. Work with them and receive report on what they are doing in those specific districts. (Edna, Ministry of Health representative)*

So, it is evident from Edna's quote above that it is the responsibility of the district health team to bring the different community stakeholders (CHWs, health centres and community leaders) onboard on a breast cancer detection programme; providing guidance to project proponents and implementers and ensuring accountability of all health programmes implemented at the community level.

6.6 Roles of Non-Governmental Organisations in Early Breast Cancer Detection

The study also identified NGOs as implementing partners in PHC delivery. NGO is presented here as an all-encompassing term for bi-lateral or multilateral donors and other national and international not for profit organisations. The significance of NGOs as *implementing partners* in PHC delivery was affirmed by both CHWs and key informants. Specifically, the study participants identified that NGOs would be the key financier of any breast cancer detection programme as they usually '*give a hand*' [Felix, HC III representative] to augment the insufficient government budget for health service delivery.

> *Just as I told you, funding in the country, 70% of our health sector is funded by NGOs unless the 30% which is funded by government is salaries and what but when it comes to handling the actual treatment and all it all comes from the NGOs and what have you.*

So, when it comes to funding that means we need someone to come on board and give a hand… Because what you know our budget is limited by the government so if we could get a non-governmental organisation which can take up something to do this sensitisation and try to go through this village health team. (Felix, HC III representative)

As a result of insufficient government funding, it is evident that there is an expectation to have NGOs *take up* the responsibility of delivering a breast cancer detection programme at the town council.

In contrast to the view shared in section 6.1.5 above about the role of the government in driving breast cancer detection programme at the community level, some other participants were of the opinion that this is better driven by NGOs. In fact, majority of the CHWs and some key informants indicated that they had more faith in the NGOs to deliver a breast cancer detection programme than the government. The main reason is distrust in government officials, for instance, Mike (CHW) recounted how politicians who have promised to deliver health programmes in the past have done so as a result of their political propaganda and failed to fulfil their promise after they attained their political position.

Ah, mostly when you talk about the Government, (laughs) in Uganda they mostly come out when it is about political time ehn someone [politician] comes when he needs services [votes/political support] from the community. At times it is those NGOs who do the great work on the ground. (Mike, CHW)

The participants further suggested that NGOs could provide transportation support to enable women attend the breast cancer detection programmes at the health centres.

Yes, transport issue it is a big thing because now when it comes to health centre II, health centres III and IV, you don't have anything, and you have a bigger community who will come to you when they have this problem where you cannot at least transport everyone to where they can be diagnosed from. Errr, that issue may also need someone to come with something at least to support. (Felix, HC III representative)

6.7 Roles of Men in Early Breast Cancer Detection

The study also established the supporting role that men, specifically, spouses can play in promoting breast cancer detection for women. Some CHWs and key informants opined that men are able to provide support once they have been engaged and provided with information about breast cancer. This makes the men knowledgeable and makes breast cancer less awkward to them.

> *If at all these men have knowledge about breast cancer, I think they can also help their wives to advise them and in case if they find out that my wife has breast cancer, it may not look awkward to him. (Caroline, HC IV representative)*

It is also essential to involve men because they are the main funders at the household level as indicated through a dialogue with Caleb from one of the NGOs.

> *Caleb: And not only the women, I think the men, the husbands, I think they can have sessions where they come to teach the men.*
>
> *Int: That's interesting, why do you think the men should be involved as well?*
>
> *Caleb: For starters, I think it will be a good thing just as we are seeing male involvement in many things because they will ideally understand as they are funders. They fund the travel to the health facility to go and do more than just screen. The thinking is that the husband will foot the transport and any health care costs incurred. So, you want them involved from the very first stage of checking their wives' breasts. I think there's that financial aspect but also the fact that they are each other's keeper.*

The participants also highlighted that men can also provide social support for their wives by encouraging her to attend breast cancer detection programmes. In the quote below, Agnes, a key informant recommended engaging men as breast cancer champions within the community, however she added that due to the gender norms the men may only be involved in creating awareness not performing breast examination. However, once the men have been educated and have received knowledge about breast cancer and how to detect it, they can perform breast examination for their wives or partners.

What we can do to involve the male, when like we do our sensitisation, we shall not say that only women. When we are making our announcement that there is this study, we want you to come and attend, we shall invite both male and female. And also, what we can do is sometimes we have them as champions. So, like once we train these VHTs we shall select some of them to be champions. (Agnes, district health team representative)

According to Lydia in the quote below, the need to involve men has also been expressed by women through their interactions with her. She further expressed that women are keen for the men to be involved in health campaigns which would otherwise be targeted at only women.

Even when we tell the ladies they say when you organise the [health] lectures invite the men because if at all you teach us alone, men will not understand what we are trying to them. And so far, we have never had the chance to organise and meet men with ladies and ladies they really inquire to organise lectures both for ladies and the men so that they also get to understand. Because if we teach the ladies [alone], they will go home, tell their husbands, they [the husbands] will just ignore but if at all they were there they would have understood. (Lydia, CHW)

6.8 Roles of Women in Early Breast Cancer Detection

Lastly, the community women themselves were identified by CHWs as stakeholders in the promotion of early breast cancer detection. As the main beneficiary of any breast cancer detection programme, the study established that women also have roles to play in active utilisation of services provided by listening to health programmes and participating in breast health programmes.

…and then to listen to health programmes on tv, radios and then they are some organisations who come to our villages to speak on different health topics so they must be attending these health education talks. (Alice, CHW)

Another role identified for the women was self-responsibility. Some CHWs and key informants were of the opinion that it is up to the women to value and take responsibility for

their health. For instance, Anita opined in her quote below that it is up to a woman to value her health and ensures she seeks the required health care.

> *Seriously, if you need life, if you know the value of life, you can look for all ways to see that you reach to the health centre. That one I can't say something because even if we want our government to help us, but it can't put a health centre to each village. I would advise people to value their life- even if the health centre is far, take your time, try your best and go there. All in all, you have to value your life, that's all I can say. (Anita, CHW)*

Lastly, the study revealed that women can act as *role model[s]* to foster peer to peer as well as general community awareness through training the trainer model. The study showed that this training the trainer approach has been successfully used in relation to the management of other diseases such as sexual and reproductive health where community members were trained as peer educators to provide sexual and reproductive health information to their peers. This concept of training women to become *role model[s]* described below by Stanley has the potential to make women zealous about the health of other women around them.

> *What we do as VHTs, every area we are told that in every village you come from, select women or youths because those are the category of people which may have a free time for our services. We train four to six people what we do. Exactly what we are trained, we train those people such that they help us to take on the message where it is needed to be a role model in our areas such that when you talk about such health issues you can refer people to them. (Stanley, CHW)*

Specifically, women who have survived breast cancer are better placed to act as role models. This is because they are able to educate women and share knowledge based on their lived experiences. As Evelyn [NGO representative] puts it, *[they] will be able to explain to them [women] how they went about it and how they were able to work through the situation.*

6.9 Discussion of Qualitative Findings II

6.9.1 Roles of the Ministry of Health in early breast cancer detection

The second theme from the qualitative data collection highlighted the need to engage with different stakeholders across various sectors, including the target group themselves (women). Engaging with these different stakeholders resonates with the original aim of the PHC concept (WHO 1978) and SDG 17: Partnership for the goals (United Nations 2015) commitment to collaborate with multi-sectoral actors. The original PHC concept as mapped out in the Alma-Ata Declaration specifically called on its signatories to commit to "formulate national policies, strategies and plans of action to launch and sustain PHC as part of a comprehensive national health system and in coordination with other sectors" (WHO 1978, p. 5). These other sectors identified as 'collaborating agents' in this study operate across different levels and comprise of a mix of bottom level community and sub-national stakeholders and top-level national stakeholders. From a top-level perspective, the study identified the Ministry of Health as the key stakeholder having overall responsibility for the formulation and implementation of policies as well as supervision of breast cancer service delivery within the country. Specifically, the key informants were of the opinion that the Ministry of Health's core roles are to provide resources, oversight, governance, and strategic direction for improved breast cancer detection across the country as is the case with their roles in the management of other health issues in Uganda (Ministry of Health 2015b). The identified Ministry of Health roles also aligns with global expectations from the national government in promoting breast cancer detection. For instance, the WHO *Package of Essential Non-communicable Diseases Interventions for Primary Health Care* places an expectation on the Ministry of Health of each WHO member state to provide leadership and oversight on PHC intervention for breast cancer detection (WHO 2010b). A recent assessment of breast cancer services in Zambia also recommended that the Zambian Ministry of Health should take a leadership role and develop national guidelines for breast cancer control (Cabanes et al. 2019). The findings from this study agree with Cabanes et al.'s (2019) recommendation that part of the Ministry of Health's leadership role is to develop a national cancer policy for sustainable cancer control. However, the Ministry cannot deliver on this responsibility of developing an NCCP which can be effectively translated into action without

interacting with the other stakeholders highlighted in this study, such as the NGOs and PHC workers.

6.9.2 Roles of NGOs and PHC centres in early breast cancer detection

The other category of top-level stakeholders identified are NGOs. The indication from this study that some participants had more faith in NGOs to provide financing for a breast cancer detection programme is typical for a country like Uganda where 70% of its PHC health financing is donor funded. This agrees with existing publications that show the roles of NGOs as key funders and provider of resources for cancer control in LICs (Cohen et al. 2014; Olateju, Sarathy and Wieland 2017). In addition, existing literature shows that NGOs have been instrumental in promoting an integrated approach for cancer control. For instance, the integration of cervical cancer into HIV services in SSA has been largely driven by the Pink Ribbon Red Ribbon initiative (Olateju, Sarathy and Wieland 2017). NGOs have also been known to contribute to research, for example, there is evidence of collaborative work between researchers and a cancer NGO in Kampala, UWOCASO (Koon, Lehman and Gralow 2013; Scheel et al. 2017). However, the support provided by NGOs come at a cost to the national health system and is fraught with its own challenges, as discussed in the next chapter (chapter 7.0). The study participants further expatiated on the roles of health centres in relation to breast cancer detection and recommended that a stratified approach to breast cancer detection be put in place due to the varying capacities of the three health centres. Although this suggestion is akin to the BHGI's recommendation to adopt a stratified system for breast cancer detection based on available resources (Yip et al. 2008), there is limited data on the implementation of a stratified breast cancer detection programme within a tiered PHC system. A recommended approach to stratify best cancer detection services across HC levels II, III and IV is detailed in the study implications chapter (section **Error! Reference source not found.**). According to the study findings, HC IV is positioned to provide diagnostic services as it possesses surgical capabilities as reflected by the availability of surgical staff such as theatre and anaesthetic assistant. Similarly, Martin et al. (2019) recommended that the capacity of district health hospital in Rwanda which bears similarity to HC IV should be strengthened to provide diagnostic services. However, further studies are required to explore the feasibility of higher-level PHC centres in SSA to provide diagnostic services for breast cancer.

6.9.3 Roles of CHWs in early breast cancer detection

The most crucial category of stakeholders identified at the community level are the CHWs. The identified roles of CHWs from this study include breast education, referral, providing breast examinations, community mobilisation, advocacy and delivering outreach services. It is important to note that the potential roles of CHWs in breast cancer detection is not so different from their general roles discussed in the situation analysis chapter (see section 4.3.2). Specifically, this study identified breast education as the core role of CHWs, thus, aligns with the existing body of knowledge which indicate that knowledge creation through breast health education begins with CHWs (Pace et al. 2018; Wadler et al. 2011). CHWs also have similar roles in cervical cancer screening across SSA as highlighted in a recent systematic review (O'Donovan, O'Donovan and Nagraj 2019). The systematic review highlighted that in SSA (specifically Nigeria, South Africa and Uganda) and other LICs, CHWs support with cervical screening by providing outreach services through education, mobilisation and performing cervical cancer examination. The qualitative findings further reaffirm the roles of CHWs as being uniquely placed to facilitate the process of engaging with community members through home visiting and providing community-wide sensitisations. The facilitation of engagement with women is a core function of CHWs as articulated by the Uganda Ministry of Health (Ministry of Health 2010b) and Bittencourt and Scarini (2019). Therefore, it can be implied that CHWs do not generally have to perform separate roles to what they currently do in other to be involved in early breast cancer detection. However, they will require capacity building to be able to deliver early breast cancer detection services as discussed in section 5.3.4. The only major discrepancy in the current roles of CHWs and their potential role in breast cancer detection may be in delivering breast examinations. Although some participants from this study and Wadler et al.'s (2011) study of CHWs in South Africa suggested that CHWs have the potential to promote early breast cancer detection through breast examination, but findings from the situation analysis revealed that most male CHWs in Kajjansi do not perceive themselves as being able to provide breast examination. In a past study which found the use of CHWs effective to deliver breast examinations in Sudan, only females where used (Abuidris et al. 2013). This indicates that there is a gender aspect to services which male CHWs, perhaps other male health workers can provide in relation to breast cancer detection. The implication

of the sex of PHC worker in relation to early breast cancer detection is discussed in the next chapter.

6.9.4 Roles of community leaders in early breast cancer detection

The study also recognised the value of community stakeholders such as cultural and religious leaders and their potential to promote breast cancer detection through education, mobilisation and gatekeeping. The value of these community leaders in promoting positive health outcomes is not only recognised in LICs but also in HICs such as the United States (Anshel and Smith 2014). The study also established that cultural and religious leaders are great influencers at the community level as they wield a great level of power and influence over their community members. So, they can be used as a point of contact to promote participation and uptake of breast cancer detection services as they have done with other health issues such as maternal and child health in Uganda, Tanzania, Nigeria, Ghana, Malawi, DRC and Mozambique (Widmer et al. 2011) and cervical cancer screening in Uganda (Carl-Spencer 2018). Furthermore, like CHWs, religious organisations have credibility (Anshel and Smith 2014) and are grounded in communities, thus making them a crucial advocacy platform. For example, Faith in Action, a faith-based organisation spearheaded a multi-country project targeting HIV/AIDs in Haiti, India, South Africa, Thailand, Uganda (Woldehanna et al. 2005). Another category of stakeholders identified in this study is institutional stakeholders. Although reliance on traditional healers is generally perceived as detrimental to women's health (Balogun and Formenti 2015), the findings show that this may not be the case if the traditional healers are engaged and well educated. As indicated in the study findings, traditional healers have played a role in creating awareness and signposting community members in the case of HIV/AIDs management. A best-practice collection of traditional healers' roles in HIV across SSA concluded that they improve health service delivery through prompt referral to the health centres (UNAIDS 2000). The findings from this second theme also evidenced the link between health and development through its suggestion of engaging with non-health specific actors such as community development stakeholders. This is also consistent with the existing body of knowledge (Walley et al. 2008; WHO 2008a) which recognises the increasing influence of the social or structural determinants of health.

6.9.5 Roles of women in early breast cancer detection

The study also identified the need for women in the community to be engaged as role models, take responsibility for their health and actively participate in breast cancer detection programmes. The study specifically showed that breast cancer survivors can be used to promote awareness and utilisation of breast cancer detection services. Uganda can learn from other LICs such as Haiti where breast cancer survivors called women health promoters were used by Innovating Health International to create breast cancer awareness and encourage BSE among women in Haiti (McCurdy et al. 2018). McCurdy et al. (2018) reported that through the efforts of these women health promoters, the number of women presenting with breast cancer at the Women's Cancer Treatment Centre has doubled. Thus, implying that increased knowledge about breast cancer prompted earlier detection and presentation of the disease at the health care centre. Using breast cancer survivors also has the potential to add a personalised element to the breast education package (Wigginton et al. 2018; Yi and Park 2012) as these survivors have gone through and survived the journey of breast cancer, thus are in the best position to educate women from an experiential standpoint, that is, educating women through experience sharing. Existing evidence shows that breast cancer advocacy is spearheaded by women who are either survivors or have lost a relative or friend to breast cancer (Anderson, Ilbawi and El Saghir 2015; Osuch et al. 2012; Scheel et al. 2018). These survivors have gone on to become advocates forming grassroots breast cancer organisation, for instance, the UWOCASO which supports with breast cancer awareness, psychosocial support and patient navigation (Scheel et al. 2018). Therefore, breast cancer survivors have a key role to play in advocacy around breast cancer control.

One of the focus of the qualitative component of this study was to explore whether and how women are engaged in PHC delivery. The findings suggest that women are predominantly engaged through CHWs and current engagement approaches for women in the community are restricted to an inactive form of engagement through information sharing. There was no indication whatsoever about how women's voices can be taken into account in designing a breast cancer detection programme. This passive mode of engagement is consistent with the typical practice of doing health 'to' rather than 'with' women (Slay and Stephens 2013). Slay and Stephens (2013) present a ladder of participation which shows how information sharing

occupies the bottom level while 'doing health with people' comprise of deeper engagement which seeks to empower individuals through co-design or co-production. This deeper level of engagement is important to improve acceptance, utilisation, adherence (McCurdy et al. 2018) and ensure the sustainability of any breast cancer detection programme. Furthermore, this study indicates the need to be cognisant of gender relations between men and women in designing breast cancer detection programmes. For example, when family planning was newly introduced, Young (1993) accounted that women lacked the autonomy and control over the choice of family planning as decisions were made by the men. The lack of autonomy is also similar to this study findings which alludes that, women, especially married heterosexual women do not have complete autonomy over their bodies as their health-seeking behaviours and actions are influenced by the support they receive from their spouses. This finding builds on a study conducted by Sayed et al. (2019) in Kenya which showed that the influence of the man as head of the household limits the decision-making autonomy of a woman in relation to seeking breast cancer care. Although existing studies have highlighted the need to involve spouses in breast cancer control decisions (El Saghir et al. 2011; Olasehinde et al. 2019), there is a paucity of data on the actual involvement of this stakeholder category. Therefore, future interventions on early breast cancer detection should ensure men are involved so as to make them knowledgeable and able to provide the necessary support for the women.

6.9.6 Roles of the District Health Team in early breast cancer detection

Perhaps, the most crucial category of stakeholders identified from this study is the district health team. The identified roles for this category of stakeholders are to implement policies, coordinate and supervise health activities at the community level. Therefore, it can be inferred that the overall responsibility for the actual delivery of an early breast cancer detection programme lies with the district health. The highlighted roles of the district health team are similar to those articulated by other authors in Uganda (Henriksson et al. 2019; Ministry of Health 2015a; WHO 2010a). The district health team is considered crucial because it is well-positioned to act as a mediator between the top-level stakeholders as well as community stakeholders. On the other hand, the qualitative data suggest that these district stakeholders are not consulted during health policy development. This is problematic for

effective policy implementation as lack of consultation with this category of stakeholder could result in the development of policies which are disconnected from community realities (WHO 2016b), thus resulting in the development of policies which do not get implemented or meet the needs of communities. Over time, this has the potential to generate distrust in the policymakers, thus perpetuating reliance of the district health team and community on other agencies such as the NGO. The study also indicates that the roles of the district health team can be hindered by insufficient funding, which could be another driver of reliance on NGOs to provide resources to implement the policies developed by the Ministry of Health. Inadequate funding has been recognised as a factor militating against the performance and authority of the district health team in SSA (Doherty et al. 2018). Therefore, there is also a need to explore and implement strategies to strengthen the district health team for effective PHC delivery.

Chapter Summary

This chapter which captures the second theme from the qualitative findings has shown that the growing problem of breast cancer in Uganda is both urgent and important and calls for coordinated efforts from the government and other multisectoral stakeholders. Hence, the focus of this chapter was to highlight the potential stakeholders and discuss their roles. The different stakeholders highlighted include the CHWs, PHC centres, women, men, district health team, Ministry of Health, NGOs, community leaders and institutional leaders. The next chapter of this thesis presents and discusses findings from the remaining four themes identified from the qualitative data collection.

CHAPTER SEVEN

7.0 QUALITATIVE DATA FINDINGS III

The previous qualitative chapters (five and six) have focused on findings relating to how to deliver breast cancer detection services at the community level and the need for multi-stakeholder engagement respectively. In this chapter, I present and discuss the remaining four themes: Perceived influence of health workers' gender; Beyond breast cancer detection; From mothers to victims and Persisting challenges.

7.1 Perceived influence of health workers' gender

The first theme discussed in this chapter focuses on understanding that multiple perspectives exist in relation to the sex of health workers delivering early breast cancer detection services for women. Specifically, findings within this theme show how gender norms around the sex of the PHC worker can have an impact on breast cancer detection service delivery. The study participants conveyed three varying perspectives around sex of health workers and early breast cancer detection which make up the sub-themes as depicted in Figure 7.1.

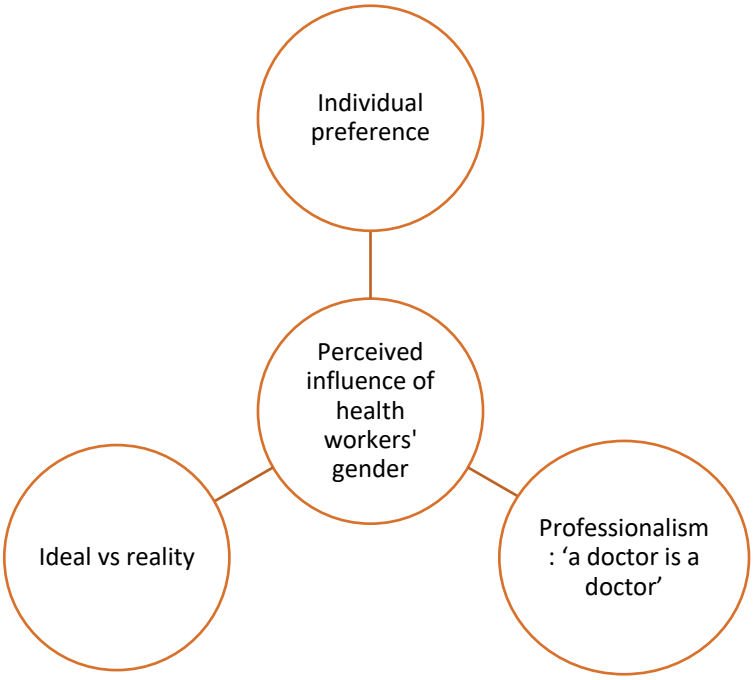

Figure 7.1: Illustration of sub-themes within *perceived influence of health workers' gender theme*

7.1.1 Individual preference

Some participants acknowledged that the sex of the health worker matters in the delivery of breast cancer detection services, but this would vary among women. Essentially, the participants revealed that the issue around the sex of health worker is based on individual preference or religious beliefs *like Muslims [women], they are not allowed to be touched by men [Lydia, CHW]*. On the other hand, the study findings indicate that this individual preference does not necessarily mean women would prefer to receive breast cancer detection services from female health workers. This recognition of a woman's preference regarding the sex of health worker was only shared among the CHWs and not the key informants. The majority of the CHWs were of the opinion that women prefer male health workers because they are perceived to be more approachable and friendly. Whereas some female health workers do not create an enabling environment to make a woman to be open. Interestingly, this view was shared by both male and female participants as indicated from the dialogues presented below between a male (Mike) and female (Beatrice) CHW.

> *Mike: That one it depends- some they want those male health workers to work on them because at times for them they are very easy. Others they say that I don't want the male health worker to check my breasts, so it depends, but such an issue can be solved when a female health worker works on the women. But most times our female health workers, you can find out that they are not approachable. Since they are not approachable, the client can be there with the pain and not want to go to her [female health worker]. So, our health workers need to be approachable. At times the males are very approachable, for them, they are very easy.*
>
> *Int: Sorry for cutting in…easy in terms of what?*
>
> *Mike: Ehhh to work on the clients. For them, at times they are ready to work. Even their approach depends but for the ladies at times the approach is very different.*
>
> *Int: What's the difference? How is the approach of the male worker different from the female?*

Mike: Like someone has come to ask you any question, for those ladies at times they don't want to give their time to talk to them or welcome them. At times those ladies [health user] they need time because that breasts they need time to say I have this, if you don't give her time, she cannot tell you. That's why it depends on the health worker for them to be open. But for this male health workers at times they give them time- what's the problem? What can I do for you? They have that welcoming approach.

This was further attested by a female CHW, Beatrice who shared similar views and alluded that the female health workers can sometimes be rude and do not maintain the confidentiality of their service users.

Beatrice: Sometimes, some they need male, some they need female. It depends on the way of approach and how someone talks to the people. Some of them need female and some of them they need male and sometimes, in our villages they need male because they know that they can't tell their problems.

Int: Why do you think some need male and some need female?

Beatrice: Sometimes these males, their approach is good and sometimes the way they handle the women is not the way women handle the women.

Int: Can you just tell me more about that? How do women handle women and how do men handle women? Can you shed more light on that, please?

Beatrice: I don't know whether women to women they are rude sometimes.

Additionally, sex of the health worker matters because of the perception that women trust men with regards to their privacy and confidentiality. The male health workers were portrayed as being more likely to protect the confidentiality of a woman than their female counterparts. For instance, a male CHW expressed that it is because women do not usually trust female CHWs because they are more likely to pass rumours about their health.

On that case [sex of health worker], some of the ladies they don't trust ladies because most ladies they have rumours and for us, some ladies, some women trust men because a man can see something and say no, I will never tell anybody but for the ladies, you can

find that ladies say no I don't want a woman to know my pain because anytime we can quarrel and she can start talking things about my life to other people. So, in that case, the ladies say no for me I talk with a man, I don't talk with women. (Steve, CHW)

7.1.2 Professionalism: 'a doctor is a doctor'

In contrast to the views shared above, majority of the key informants and few CHWs were of the opinion that sex of health worker does not matter because the health worker is defined by his profession, not his sex. It is important to note that these are all views from PHC providers and not the service users. Hence, what to look out for is professionalism and quality of health service, not the sex of health worker. To reinforce this, Constance highlighted below how it is not an issue to have a male doctor during pregnancy and childbirth.

I don't know about that. What I know you can be pregnant, and you can be helped by a male doctor. For me, in fact, I don't know that it can be a problem to meet a male doctor. (Constance, CHW)

On the other hand, Felix, a key informant found it unbelievable that a woman would not feel comfortable to have her breasts examined because of the sex of the health worker. In his opinion, this could be an excuse by the woman to cloud her fears of utilising breast cancer detection service.

Eh [sounded surprised] I don't know why she said that, but I don't believe that…I don't really buy the issue of maybe the sex is affecting them. Maybe somebody just fails to address this issue [of breast cancer] properly and she fears. (Felix, HC III representative)

7.1.3 Ideal vs Reality

Lastly, this sub-theme revealed that the sex of the health worker should not be a problem because sex should not be a factor because the ideal PHC delivery system is that women are given an option to choose between a female and male health worker as stated by one of the male CHWs, Vincent.

We give them options, for example, if they have come for ante-natal, they can choose the health worker they like because there are male midwives and female

midwives. So, some of them choose to go with the male, others choose to go with the female. (Vincent, CHW)

However, Agnes, a female key informant clarified that although the ideal requirement is to have the option offered to women that this is not usually the case in reality.

In that case, what is supposed to happen is normally when the health worker is a male, that male is supposed to be with a female nurse at least to be there by their side and that is what is supposed to be done. Only that being in Africa somehow somewhere that does not happen. You find yes that the clinician is a male, and the woman comes, and this person is the one going to examine her. Also, there is need to inform the health workers about that, you know what, if you are male then some women may not feel comfortable to examine but you know because they study it in school and stop there. Like somewhere they forget about it so they also need to remind them that much as you are a male clinician if at all a sensitive issue comes up maybe like breast checking at least you can work with a female nurse so that the person is not feeling uncomfortable. (Agnes, district health team representative)

Agnes quote above expands that what would be more practical and ideal is to have a female nurse as a chaperone *to be there by their side* during CBE. However, she admits that this does not also happen for different reasons including lack of refresher training for health workers and organisational culture associated with the African PHC setting.

7.2 Beyond Breast Cancer Detection

This theme presents findings beyond breast cancer detection that are nonetheless important for comprehensive breast cancer control. The findings from this study suggest that focusing on breast cancer detection actions alone is insufficient for effective breast cancer control. Specifically, the study established that beyond breast cancer detection, there is the need to strengthen the referral pathway, provide diagnostic services, improve access to affordable breast cancer treatment and integrate breast and cervical cancer screening as summarised in Figure 7.2.

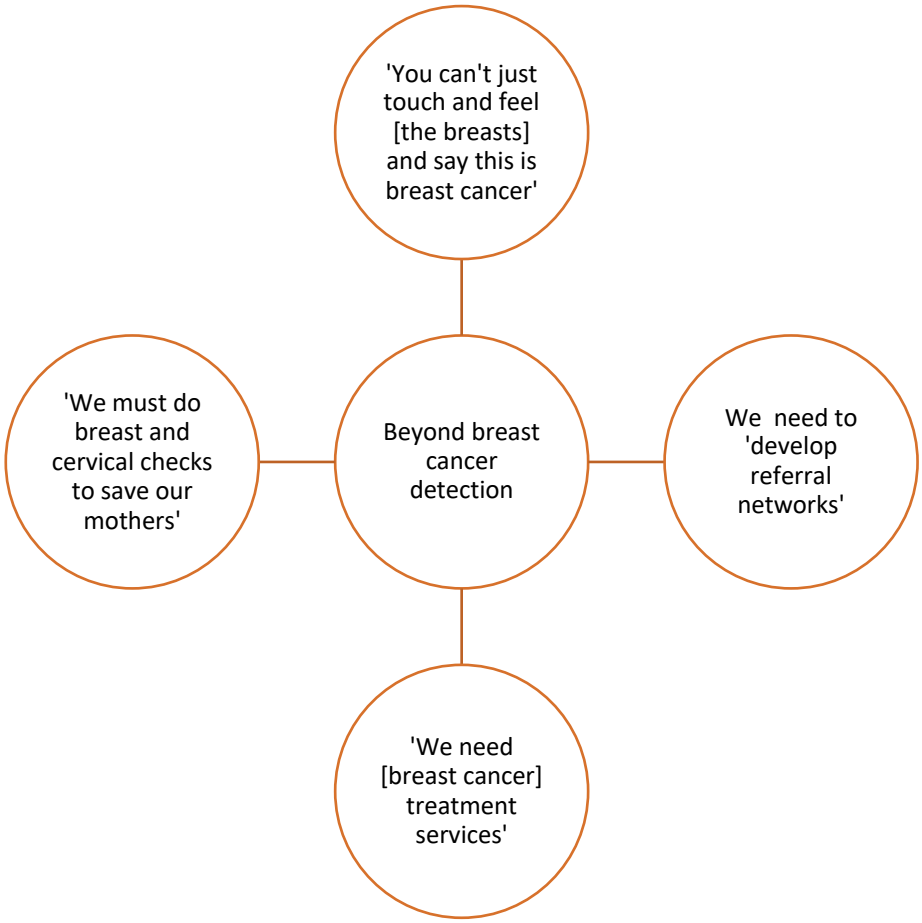

Figure 7.2: Illustration of sub-themes within beyond breast cancer detection theme

7.2.1 'You can't just touch and feel [the breasts] and say this is breast cancer'

Beyond detecting breast cancer, the study participants advocated for the need for breast equipment to support with breast cancer diagnosis, especially at Kajjansi HC IV which is able to offer surgical services to remove suspicious breast tissues and further provide laboratory services to test the mass for cancer cells (as presented in section 6.2). Lydia, a CHW stated that providing diagnostic services is the *main thing* in order to ensure that only those women who need referral are actually being referred. Without diagnosis, the PHC system *fails to provide the service needed* [Alex, CHW] for breast cancer control. Some CHWs made specific reference to diagnostic examinations through mammography screening or ultrasound scans by expressing the need for *machines*, *instruments* or *scanners* to check the breast as seen in John's quote:

We need some machines which can be used to check this person has breast cancer, we need some instruments to know that one have or does not have, to know the number of people who have and refer them. (John, CHW)

A key informant, Kelvin, further elaborated that training health workers at the health centres is futile if there is no breast cancer equipment in place.

For the government facilities, let the government, the stakeholders provide what it takes for it [breast cancer diagnosis] to be done at the facilities. The health worker can be there with all the information, knowing what to do at the facility but he can't help that patient or that woman because he doesn't have what to use. So, let the stakeholders provide what is necessary for the government facilities so the health team can provide that service [breast cancer diagnosis] to their clients. (Kelvin, HC II representative)

7.2.2 We also need to 'develop the referral networks'

In addition to providing early diagnostic services, the study identified the need for the government to establish a coordinated cancer referral system so that women who have been examined and diagnosed at the PHC centres can then be effectively referred to secondary or tertiary hospitals for early treatment.

They [the government] need also to develop the referral networks because screening is just one thing and maybe when you talk of screening at the community level, most times it's just touching the breast to see or observing to see that there is a change or there is a lump. But usually, by the time you can actually see the change with your eyes it means it is already advanced, there's a wound but the early stage when you can't even detect that is what the community should be doing, and such people should be sent early as those can be addressed and maybe operated upon and they get better. (Sharon, NGO 4 representative)

The interviews further revealed that the health centres at Kajjansi town council did not have an effective system of tracking and following up on women who have been referred to secondary or tertiary hospitals. Felix, a key informant reported that the health centre provided women with a paper-based form upon referral. However, it is difficult to track the

continuity of care with a paper-based system as shown through the dialogue below with the representative from HC III:

> *Int: Okay. Is there a way to track patients? Does every patient in your health centre have a unique ID that can be used to track them as they are being referred to Entebbe?*
>
> *Felix: Yes, yes yes. Actually, what we have, we have a form which tracks them down. When we give referral form it always has that paper that they bring back after referral and when they are also bringing back the patient, they also write to us and tell us that this patient has been discharged and is now under your care.*
>
> *Int: But then the patient has to bring the paper back to the health centre, right? What if the patient doesn't bring it back, how would you track the patient then?*
>
> *Felix: if the person doesn't bring back the paper then it becomes difficult because you may fail to know whether he went because some of them you refer them to Entebbe [regional referral hospital] and they decide they don't go there so it becomes difficult to track them.*

7.2.3 'We need [breast cancer] treatment services'

The study participants further emphasised the need for affordable treatment facilities. Specifically, the CHWs reported that whenever women come to them for any health concern, their key focus is *who is going to give me the right treatment?* [Kate, CHW]. For instance, one CHW stated that:

> *I think on that we want you to help us so that if they find that they are having breast cancer even the treatment must be there and because if someone has told you that actually you are having breast cancer [and]the treatment is there, that is okay. (Bianca, CHW)*

Bianca's opinion from her quote above is that telling someone that she has breast cancer without providing treatment services is not okay. Bianca's use of 'okay' in her quote suggests ethics of breast cancer control and how making follow on breast cancer control services available post-detection is ethical in terms of breast cancer care delivery.

7.2.4 'We must do breast and cervical checks to cave our mothers'

The study findings also suggest the need to look beyond breast cancer control as this is just one of the many cancers affecting women. For instance, Alice (CHW) was of the opinion that breast and cervical cancers are associated due to the ability of cancer cells to *move in the blood*, so a woman having cervical cancer is susceptible to breast cancer as the cancer cells can move around the blood from her vagina area to her breasts and vice versa.

> *Alice: We must do breast check and cervical cancer check to save our mothers.*
>
> *Int: I have observed that when you talk about breast cancer, you also refer to cervical cancer. Why do you think the two go hand in hand?*
>
> *Alice: Because cancer moves in the blood. So, it can move from up to down [points from the breast area to vagina area] or down to up [points from vagina area to breast area].*
>
> *Int: Just to be sure I get you- are you saying that if a woman has breast cancer, that can make her have cervical cancer as well?*
>
> *Alice: It can because it can move around the other parts of the body. So, we can focus on breast and forget about cervical cancer whereas it is also dangerous to us women.*

Therefore, from Alice's suggestion, the focus should not only be on breast cancer but taking an approach that integrates breast and cervical cancer to improve women's health.

7.3 From Mothers to Victims

The fifth theme from the qualitative data collection presents the shifting identity of a woman from mother to victim in relation to breast cancer control as presented in Figure 7.3.

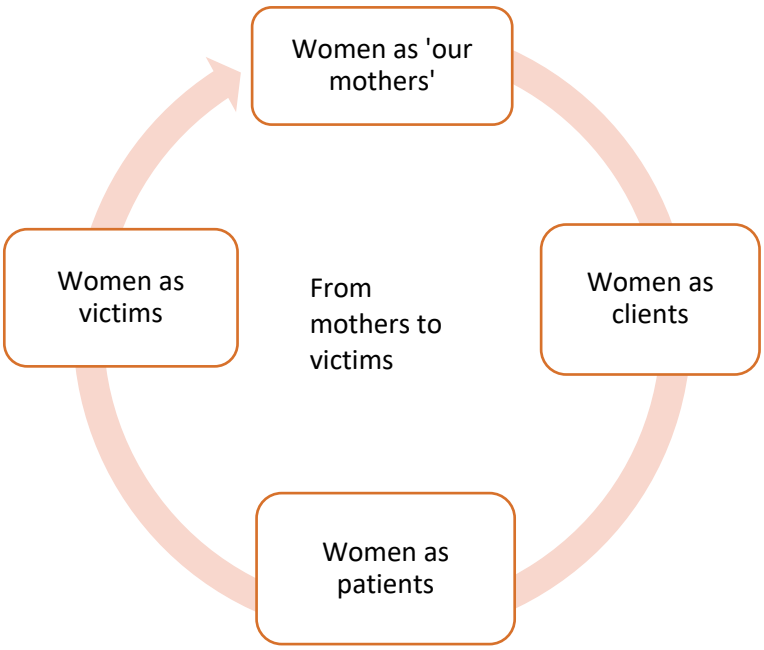

Figure 7.3: Illustration of subthemes within from mothers to victims theme

The language used by the study participants to refer to women during the data collection also alluded to thinking comprehensively about breast cancer control. CHWs generally acknowledge women for their roles as mothers and referred to women as 'our mothers' or 'clients'. For instance, Alice (CHW) pointed out that *health workers can teach every mother to regularly check their breasts.* This implies mother is used as a general description for women at the community level who have not yet entered into the formal healthcare system.

> *First of all, what we need to do is to create awareness because I must tell you, Deborah, mothers are not aware. They feel they are not at risk; their perception is so little; they feel they are not at risk at all. You know like mothers come [to the health centre], maybe she comes, she has a swelling in the breast and says like my breast is paining me…I will refer these mothers to Mulago Cancer Institute for further investigations (Agnes, district health team representative).*

However, Agnes above used 'mother' as a generic term to describe women generally, whether within or outside the healthcare system. In fact, Agnes used the term for mother at any point of the breast cancer control continuum.

Reference to women as clients was also used by CHWs as a broad term to describe a woman who is being provided with health services by the CHWs.

> *At least, if they [government] set up like meetings or training to the village level because we the VHTs we can coordinate, and people can come of course at least we are trained. When we've got enough training, we can talk to the clients and come for a meeting but on the village level. (Anita, CHW)*

What is evident from Anita's quote above is that a client is a health service user. Here, Anita was talking about how the government can set up community outreaches and train CHWs so that they can *talk to the clients* about breast cancer.

On the other hand, male key informants and some male CHWs referred to women as patients. The reference to women as patients was used by the male participants not only to describe women who have been referred to or receiving care at the health centres or hospitals for one health issue or another, not necessarily breast cancer but also women who are still based within the communities. For instance, Felix's reference to women as patients in the quote below was used as a broad term to refer to both women who were being treated at the health centres and those within the community.

> *If we can get that chance at least teaching every patient about cancers and breast cancer and everyone has knowledge about it so it can be addressed. Even the patients down there in the community, we can teach them about this breast cancer. (Felix, HC III representative)*

Lastly, women were referred to as victims when participants were discussing women who have been diagnosed or have gone through the experience of breast cancer. For instance, in the case of a key informant working with an NGO which provides support to breast cancer survivors, the respondent's description of women was constructed around the word *victims*.

> *So, then what we can do, if we come and find out that you are victim…we can refer the victim and we can encourage the victim and we can teach the community more about that breast cancer…If you give a referral to a victim in the community, you feel good if that victim is treated there. (Constance, CHW)*

From the quote above, it is obvious how Constance made a distinction between those who have been identified with breast issues (*victims)* and the entire community. According to Constance, while the community can be educated about breast cancer, it is only a victim who gets referred for treatment.

7.4 Persisting challenges

Although this study focused on examining how the existing bottlenecks with early breast cancer detection can be addressed, the qualitative findings still highlighted some challenges which are captured within this sub-theme. The identified challenges are presented in Figure 7.4.

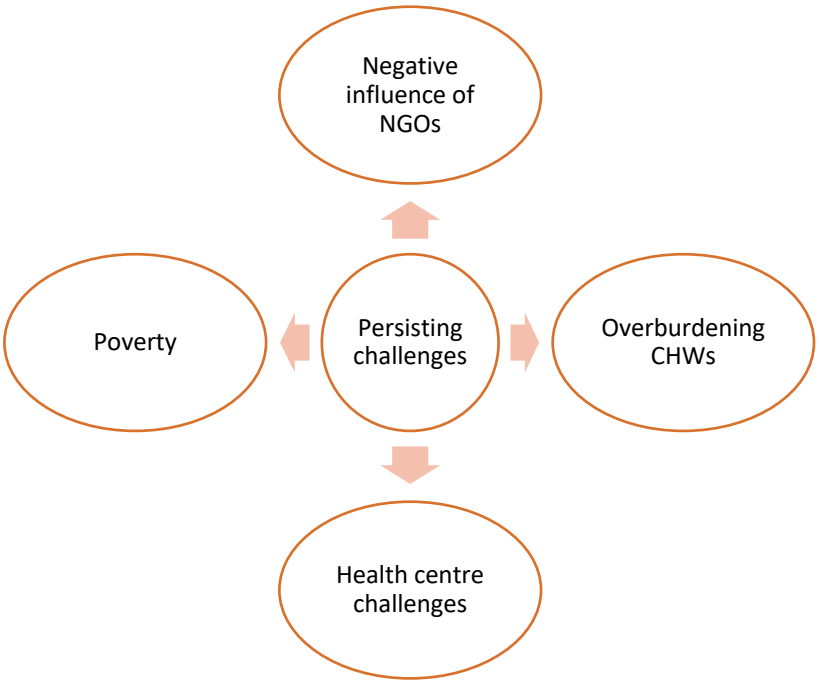

Figure 7.4: Illustration of sub-themes within persisting challenges theme

7.4.1 Negative influence of NGOs

Although the study identified the role of NGOs as key implementing partners who support with funding for implementation of PHC programmes (see section 6.6), there was also an indication that these NGOs consequently drive health priorities within the communities.

> *An implementing partner comes and say me I'm going to do testing of HIV, there is no way the district health officer is going to say that maybe cancer because for her that*

implementing partner, what he or she wants at that moment is what he has in his proposal, you understand? So, it becomes a challenge for us. (Agnes, district health team representative)

Agnes problematised this influence of NGO in her quote by explaining how it renders the district health team somewhat powerless as the NGOs have the funds to address health issues within the communities.

Mary [NGO representative] elaborated on Agnes' explanation that the NGOs have negative influences on health service delivery in Uganda as some NGOs operate independently outside of the government's health agenda.

What is a very common mistake that partners make and is so exhausting is that partners will design their own little programme and get started and then bring on the government after. And if you want anything to be taken over by the government or to be scaled up to other communities, the government has to be part of the design phase, so they know the inside and out of that programme. And they also need to be very aware of all the costs that are associated with it. So, the partners could cover a lot of the costs but if the Ministry or local government isn't aware of the costs, they will have no idea of the cost-effectiveness of the initiative. (Mary, NGO 3 representative)

According to Mary, the implication of this lack of engagement with the government and misalignment of NGO's projects with the government's health agenda is lack of sustainability as the government is unable to take ownership of such programmes.

In order to address this challenge, active engagement between the government and NGOs was emphasised as this has not been done effectively with regards to other diseases. It was reported that NGOs often work in isolation and create governance and coordination issues for the government. In order to encourage NGOs engagement with the government, Mark (district health team representative) recommended that it *is critical that they sign a memorandum of understanding with the district* in order to integrate with the District's health programme and priorities.

7.4.2 Overburdening CHWs

Another major challenge identified by the key informants and some CHWs relates to the expectations placed on CHWs to be responsible for delivering breast cancer detection at the community level.

> *It is important to know that in Uganda, that there is a long history of the VHTs, and the current situation is that government has not been able to manage these CHWs and just sort of lost their grip on the governance of this programme. What happened is partners have taken over. We found out that CHWs even when you are incentivising them, there is a fine balance between how much incentives you give them and their responsibilities…CHWs just can't do everything. So, there has to be a manageable package that they are working on…Partners are creating such a terrible mess to motivate and sustain CHWs in the country that I doubt any CHW will once the funding really stops actually continue to do the work. So, for example, the breast cancer awareness programme will happen for as long as you or another partner is providing training, transportation refund or other incentives. And they deserve those support but it's important to look at behind the scenes, what is actually happening, and I think we already have so many champions in the country, but we are treating them unfairly by saying these people are eager, let's just put everything on them. Integration of health services is good but practically, the CHWs have a lot to handle. (Mary, NGO 3 representative)*

Mary also critiqued the NGO's influence and how they are *creating such a terrible mess* of the CHWs programme. She highlighted how the CHWs programme is mismanaged by the NGOs and how the government is not taking responsibility for the CHWs programme. According to her, mismanagement by NGOs, lack of coordination and expectation of CHWs to deliver on various health programmes could potentially cause overburdening of the CHWs.

Although Mary's quote highlights the potential challenge of excess workload around the roles of CHWs in breast cancer detection. However, some CHWs expressed that they can manage the extra responsibilities:

Int: So, you said every VHT has a work plan, who determines or designs the work plan for VHTs?

Anita: We ourselves

Int: Okay, but seeing as you already work on communicable diseases like malaria, HIV, if you had to do breast cancer won't it be too much workload for the VHTs. How will you manage your workload?

Anita: Everything can be managed depending on someone's programme. Though we have to do some other things like our own businesses, if we are informed earlier, you can set up or you just decrease on the other programmes like HIV awareness, hygiene and sanitation. So, you fit in that programme of [breast] cancer training.

Similarly, a key informant who is also a CHW attested that though it is a lot of work CHWs are in the best position to provide breast cancer detection services as they reside within the communities they serve.

Really, it is too much work but since we are based in the community, we live in it so it doesn't mean that we are going to move from one community to another. For us, we are there down in the same community so it's very easy to get to them. Like someone is pregnant, you talk about all the necessary on health and you can pass that information about breast cancer. (Lillian, NGO 5 representative)

Lillian, in the quote above, can be seen making reference to integrated service provision which in her opinion does not translate to additional workload, especially since they *are there down in the same community* with the women.

7.4.3 Health centres challenges

Two challenges were highlighted at the health centre level that could potentially hamper the successful delivery of early breast cancer detection services. The first is around the commodification of health services and the second is related to a shortage of PHC staff. In relation to the commodification of PHC services, an interaction with NGO 1 representative (Evelyn) revealed that although health services at the PHC level are supposed to be free, this

is not necessarily the case. Evelyn explained that the services are affordable compared to a private hospital. According to her, this is as a result of the commodification of health care whereby sub-standard health services are free while access to *good health* has to be bought.

Evelyn: We pay for health services at the health centres

Int: At the health centres? I thought they were free, and you don't have to pay

Evelyn: we do pay. What I will just say is that it is not as expensive as the private health centres, but you pay a lesser charge. Basically, health is viewed as a commodity. So, to get good health, you buy it. Before you buy it, you have to be able to afford it. So, if you are not able to afford it then it becomes difficult. They may not pay as much as they would to the private, but they still pay something. Those medical personnel, they have families, they have responsibilities, so they also need the money as well.

Int: But I thought they were paid by the government, being a government institution.

Evelyn: No, let me tell you. That's the other thing, our policies this side are not that so good whereby they put a policy saying that government officials and personnel will be paid at so so point. But you find someone, a doctor demanding money for three good months back. So literally, you are the ones tempting those doctors to put the prices there.

Another health centre challenge highlighted was in relation to building the capacity of the PHC staff. According to Caroline [HC IV representative], building the capacity of PHC staff to provide breast cancer detection services may be complicated by the shortage of health workers. In her quote below, it is evident that leveraging on antenatal services for breast cancer detection is challenging as about 150 mothers attend antenatal and are only attended to by one or two midwives.

In fact, I have to tell you the real thing. Not really because of the numbers, the numbers are many and of course, the workload is too much and remember these mothers who come for antenatal they are so many because for antenatal you have something like 150 mothers and remember you may find that there are only one or two midwives on duty,

and she cannot examine everybody so that is also a challenge. (Caroline, HC IV representative)

7.4.4 Poverty: the 'mother of all challenges'

Although poverty is not so *alarming* [Agnes, district health team representative] that it would prevent a woman from detecting breast cancer early at the PHC level, the qualitative data collection indicated that poverty remains the *mother of all problems, of all challenges* [Vincent, CHW]. By referring to poverty as the mother of all challenges, Vincent infers that all other challenges are offshoots of this.

Also, because poverty has far-reaching consequences as it might influence access to care for subsequent spectrums in the breast cancer control continuum, particularly in relation to accessing diagnostic and treatment services which require out of pocket costs from the women. For instance, Alice in the quote below identified poverty as challenge to seek follow on care beyond breast cancer detection.

Poverty- just because poverty involves transport to go to nearby health facilities whereby if you don't have money you will not reach that health centre and if you don't go to the health centre you cannot be referred to Mulago. And even at Mulago there they need money… When those xxxxx [NGO's name withheld for confidentiality] when they came in 2017, they were screening cervical and breast cancer, one of my friends was found with signs of cervical cancer and when she went to Mulago she was asked to pay some money. So, someone from the village can go to Mulago to be screened and they say pay so so amount and when one is not having the money. They can also tell you to buy tablets of which they are expensive. (Alice, CHW)

Felix explains below how poverty at a health system level affects community outreaches.

Then it needs this community teaching because here we have what we call outreaches where you go to the community, the chairperson mobilises the people then you take them through those teachings but sometimes, we don't do it because we have little funds. You may find in a month we have to do only one outreach meaning in 3 months you do only three outreach[es]. Yet we have more than six parishes which are more than

fifty-three villages and this needs to go village by village to be sensitised. (Felix, HC III representative*)*

The study further identified addressing poverty related challenges through grassroots economic empowerment. The study established that economic empowerment can either be achieved through self-organised initiatives or government or NGO supported poverty alleviation schemes. For instance, Lillian who is a CHW but recruited as an NGO representative for this study recounted how she empowered herself and now she self-organises and train women in her communities on skills acquisition to enable them to make an income.

Lillian: For the women groups, I let them get to understand that at least they can earn a living after giving birth and give them skills like tailoring, hairdressing, baking.

Int: So, you teach these women these things? Is this part of an organisation or do you do it individually?

Lilian: It is not an organisation because it is not funded by anyone. I collect very little money like 50 pence to buy the materials.

Int: So, they contribute money for you to buy the materials for training them?

Lilian: Yes, but the teaching I do it freely.

Int: Did you receive training from any organisation to do this?

Lilian: No, since I gave birth to my children at an early age, I had to look for something to earn a living. So, whenever I find something that I can do with my hands I pay myself to learn them. Then I thought and wondered what can I do for my community so I mobilised them and said I can train you on something like this.

Participants also expressed that women can be empowered economically through poverty reduction schemes by the government focused on vocational skills building. According to Stanley (CHW), SME development has the potential to lift women out of poverty and address the challenge this poses to access to health services as it *enable[s] them to get their own money.*

Really, the government have tried to empower people- the women and the youths. There are some organisations and programmes being set by the government specifically for the youths and the women and they have been training them vocational skills which can help them and enable them to get their own money not looking for a person to employ him or her. The government have come out with that programme, it is now going on, people are trained. (Stanley, CHW)

7.5 Discussion of Qualitative Findings III

7.5.1 Perceived influence of health workers' gender

This third qualitative findings chapter presents the remaining four themes identified from the study which identified perceived influence of health workers' gender, the need for breast cancer detection follow-on services, shifting identity of women in breast cancer control and challenges which may inhibit breast cancer control. From the study findings, the views around early breast cancer detection in relation to the sex of the health worker were contentious and subjective, suggesting that these views are socially constructed. Analysis of this theme portrayed participants' perceptions around the sex of health workers as individualised and culturally constructed, thus expanding on the work of Chodorow (1995) that the social construction of sex is "inevitably personal as well as cultural" (p. 517). Contrary to prevalent conceptions from service users as revealed through past studies that women are generally reluctant to have a male health worker palpate her breasts (DeSantis et al. 2015; Ilaboya 2015), findings from this study indicated that this may not always be the case as indicated by the CHWs and PHC key informants. In fact, the study findings highlighted that having a female health worker could deter a woman from detecting breast cancer early mostly because of issues around confidentiality and manner of approach. This agrees with past studies which reported that female CHWs were not trusted because of unprofessionalism and their inability to maintain confidentiality in providing maternal and child health services in South Africa (Grant et al. 2017) and HIV services in Swaziland (Geldsetzer et al. 2017). These authors further opine that lack of trust in CHWs could undermine their roles and impact negatively on the acceptability of services and also be a demotivating factor for the CHWs themselves (Grant et al. 2017; Okello and Gilson 2015). Therefore, the sex of health workers should be

taken into consideration when designing a breast cancer detection programme to ensure optimum acceptability.

Although this study's findings further suggest that the sex differences around confidentiality and trust apply to both PHC staff and CHWs, Geldsetzer et al. (2017) opine that this is not the case as PHC staff have a higher level of training, thus would exhibit a greater degree of confidentiality and professionalism. This agrees with the indication from some participants in this study that the sex of a health worker itself should not be an issue and the focus should rather be on professionalism. Therefore, further studies are required to address the complex interaction of gender and confidentiality among CHWs through context-specific training on professional and confidential client relationship. Also, the study findings allude to how gender considerations might be different for other health issues like maternal health where it was specifically highlighted that it is not a problem for a male doctor to attend to a woman during pregnancy and childbirth. This was also indicated in the situation analysis findings where almost all the CHWs surveyed (n=288; 98.6%) provide maternal health services still a majority (n=282; 96.6%) did not think male CHWs could provide breast cancer detection services. This suggests that there might be differences in how sex of health workers is socially constructed across health issues. Therefore, the sex of the health worker should not be taken as a generic or fixed concept (Eveline and Bacchi 2010) and its implication should be considered in relation to the specific health issue. Lastly, the study revealed that due to constraints of the shortage of health workers in most SSA settings, it might be difficult if not impossible to request sex preference for a health worker. However, the study suggested the use of chaperones which have been recommended by other authors to address the potential gender issues relating to the delivery of health services that are considered as intimate (Dhai et al. 2011; Thuraisingham, Nalliah and Sinniah 2017). Specifically, Dhai et al. (2011) relate the option of a chaperone as being professional in PHC service delivery for intimate health issues. Therefore, due to the complex and dynamic perspectives around the sex of health workers, this study recommends the need for a gendered approach. The principles of such gendered approach should include context specificity, cultural appropriateness and professionalism.

7.5.2 From mothers to victims

Though it may not have been the original intention of the participants, they used different words which connote the changing identities of a woman at different points of the cancer journey (Park, Zlateva and Blank 2009). The dominant language used by the study participants to refer to women was mothers. This reinforces the findings from the situation analysis which revealed that there were specific services delivered to women with regards to their position as mothers such as maternal health, family planning and breastfeeding services (see section 4.1.2). However, it would be misleading to state that breast cancer detection programmes should only be targeted at mothers as breast cancer also affects young women with no children (Hjelm et al. 2019; Naku et al. 2016). The study participants also made reference to women as patients. The use of the word patients connotes recipients of medical care (Bonsu and Ncama 2019) as evidenced in articles which refer to women who are currently undergoing breast cancer treatment as patients (Agbokey et al. 2019; McKenzie et al. 2018b). Although the study also showed that some participants especially CHWs referred to women as clients, Whyte (2013) suggests that this term means a generic "user of professional services" (p. 149) and emerged in Uganda during the HIV/AIDs epidemic where those with the disease were being supported through long term care. Hence, unlike the patient, which is more of a passive title, clientship encompasses dialogue and long-lasting relationship (Costa et al. 2019). Therefore, a woman who has been diagnosed with breast cancer can be a client of any breast cancer control measure depending on her breast cancer journey. Lastly, women who are known as victims have been through the breast cancer experience and survived it. Existing literature has described the word victim as having a negative and victimising connotation (Kaiser 2008; Park, Zlateva and Blank 2009). According to these literature, women who have gone through breast cancer experience should be referred to as survivors as this is supposedly empowering and positive. Understanding the languages used to describe women also points out to the need for a gendered approach and has implications when defining the target group and their engagement in breast cancer detection or control programmes.

7.5.3 Beyond breast cancer detection

Beyond breast cancer detection, findings from this study also revealed the need for strengthening the referral pathway, providing diagnostic services, and providing affordable breast cancer treatment. This substantiates what is already known that while early breast cancer detection is crucial, it is insufficient and requires prompt diagnosis and treatment (Vento 2013; WHO 2017a). The findings particularly indicated that without having diagnostic services in place, the PHC system cannot effectively contribute towards general breast cancer control and there will not be a substantial impact on reducing the burden of breast cancer at the national referral hospital. Although providing diagnostic services at PHC level may seem like a resource-intensive endeavour, a stratified approach presented in the next chapter (section **Error! Reference source not found.**) offer possible guidance on how this might be i mplemented. Additionally, past studies have found that the use of point of care technologies such as breast ultrasound (Haney et al. 2017; Tetteh and Faulkner 2016) and novel handheld diagnostic device such as the ibreastexam (Broach et al. 2016) offer a cost-effective potential to strengthen PHC systems for breast cancer diagnosis in LICs. There was an indication from Broach et al. (2016) that the ibreastexam device can be used by CHWs and technicians, thereby suggesting simplicity in design and low technical skills requirements. This further reinforces the appropriateness of such a diagnostic tool for PHC staff. Existing literature also suggests that putting in place post-detection capacities, that is diagnostic, referral and treatment system is ethical and should precede any population-based breast cancer detection programme (Finkel 2018; Martin et al. 2019). This implies that population-based breast cancer detection can be a feasible option for Uganda or LICs in general if there are strong referral and follow on services in place. Although these findings echo Anderson, Ilbawi and El Saghir (2015) that the "[c]omponents of comprehensive breast cancer care cannot be dissociated" (p. 116), it is important to note that there may be a need for dissociation in terms of practicalities around implementation. Certainly, the lack of comprehensive breast cancer control strategies should not prevent the implementation of independent strategies for the different breast cancer control spectrums.

Another finding from this study in relation to comprehensive breast cancer detection is the need for an integrated approach which combines breast cancer detection with prevention

and detection of gynaecological cancers. The most common gynaecological cancer is cervical cancer which is currently the leading cause of female cancer in Uganda (Ferlay et al. 2018) with others been ovarian and endometrial cancer (Shetty and Garza 2014). This bears similarities to the discussion in chapter five (section 5.3.2) around leveraging existing PHC services, specifically those which target women. A practical example of an integrated intervention is the public-private breast cancer control demonstration project in Zambia which leveraged on an existing Cervical Cancer Prevention Programme to enhance the capacity for breast cancer care (Pinder et al. 2017). The programme was based on a see and treat approach for cervical cancer and integrated a single visit approach to promoting breast cancer detection. The value of a single visit approach has also been recognised by other authors such as Shetty and Garza (2014) who recommended the concept of a well-woman clinic to provide integrated services. The single visit approach has also been implemented for cervical cancer detection in Uganda (Black, Hyslop and Richmond 2019; Carl-Spencer 2018). Hence, learning from the Cervical Cancer Prevention Programme experience and other single-visit cervical cancer interventions, a comprehensive approach combining breast cancer detection with the existing cervical cancer screening services could be a feasible option for the country. Based on the success of the programme in Zambia, it has now been integrated as part of the cancer prevention arm of the Ministry of Health (Pinder et al. 2017). While this initiative shows promising success for Zambia and similar countries, its focus was on higher level hospitals, not PHC centres. However, lessons can be drawn from this approach and adapted for PHC systems.

The public-private partnership (PPP) model used in the Cervical Cancer Prevention Programme reinforces the need for a collaborative approach which has already been established from this study findings in chapter 6.0. A globally recognised example of the PPP model in cancer control practice is the Pink Ribbon Red Ribbon Initiative whose mode of operation is based on leveraging on existing vertical health programmes, particularly HIV for cervical cancer control (Oluwole and Kraemer 2013). Another notable example of a global PPP model is the partnership between Pfizer, a pharmaceutical company and the Union for International Cancer Control (UICC). The UICC-Pfizer partnership has been instrumental in providing funds and capacity building for addressing metastatic breast cancer at a national

level through its *Seeding Progress and Resources for the Cancer Community Metastatic Breast Cancer Challenge* (UICC 2019). At a national level, the PPP model has been recognised as a creative platform for health care financing to foster cancer control in LICs (Nwogu et al. 2016). This has been implemented in Nigeria where a PPP was set up comprising of oncologists, academic institutions, private enterprise and international organisations. This led to the establishment of a local NGO whose objectives were to "promote capacity building, establish collaborative networks, and develop a facility to provide clinical care" (Nwogu et al. 2016, p. 2) focused on different spectrums of the cancer control continuum. In relation to breast cancer detection, a PPP in neighbouring eastern African countries, Kenya and Tanzania comprising of Aga Khan development network, healthcare institutions from both countries, civic organisations and local authorities promoted breast cancer detection through breast cancer awareness and CBE (Talib et al. 2019). Despite it being a notable and laudable platform, PPPs are not without tension as they are driven by neoliberal reforms (Global Health Watch 2017) and lack unbiased evidence base to support their effectiveness (Parker, Zaragoza and HernÃ¡ndez-Aguado 2019). Notwithstanding, this study recommends further exploration of the benefits of public-private partnerships in delivering high-impact, scalable and sustainable breast cancer control services in Uganda.

7.5.4 Persisting challenges

While there is an opportunity to synergise breast cancer detection with existing PHC services, other health systems issue specifically those relating to shortage of primary health workers needs to be addressed to prevent straining the existing workforce (Anderson et al. 2017), especially the CHWs. Without doubt, CHWs are integral to breast cancer detection but this raises a crucial question of how to strengthen the CHWs without overburdening them? This issue has been highlighted in relation to CHWs role in NCDs management generally (Abdel-All et al. 2019; Mishra et al. 2015; Mishra et al. 2019). The debate around this very important question should not only happen among researchers and policymakers but with the CHWs themselves. The qualitative phase of this study provided an opportunity for CHWs to give their thoughts on whether or not they would feel overburdened with breast cancer detection roles. The study findings showed that even though CHWs admit that it is extra workload, but they perceive that this additional workload can be managed. That said, there is a need to look

into sustainable options especially since CHWs in Uganda, as well as many other SSA countries, are volunteers. A possible way to mitigate this concern of overburdening CHWs might be to have a specialised cadre of CHWs whose focus would be on breast cancer or NCDs in general. The set-up of this specialised cadre of CHWs can be similar to iCCM service delivery as shown through the situation analysis findings 4.3.2. The implication of this approach is that only selected CHWs are expected to provide breast cancer detection services, hence, that prevents overburdening of the entire CHWs. The iCCM model has been recognised as a cost-effective approach for promoting UHC around targeted health services (Nanyonjo et al. 2019), hence, there is a need for studies to explore this possibility for breast cancer detection.

The other challenges around CHWs contributions to breast cancer and NCDs control are funding and sustainability. Funding for the implementation of health programmes at the PHC level is oftentimes project-based and supported by NGOs (Nanyonjo et al. 2019; WHO 2016b). Whilst this has been helpful, especially in providing training and incentives for CHWs, it poses an issue of sustainability. For instance, the study found out that investment in the CHWs programme in Uganda has increasingly become the responsibility of NGOs. This is not a new issue as it has been recognised in a recent review (Nanyonjo et al. 2019) and the Ministry of Health who attributed the NGOs' responsibility in the CHWs programme to the declining government funding (Ministry of Health 2015c). Specifically, a national assessment of the CHWs programme in Uganda established that the money allocated by the government in a financial year to train the CHWs nationally is insufficient to cover training in one district (Ministry of Health 2015c). Insufficient funding for CHWs programme can result in demotivation which could eventually lead to attrition and sustainability challenges (Mays et al. 2017). Therefore, the onus goes back to the national government to prioritise taking charge of the CHWs programme to ensure sustainability. However, a recent publication which shared findings from a project implemented to support the CHWs programme in Wakiso district through training, supervision and motivation showed that the project engaged with various stakeholders in order to foster sustainability (Musoke et al. 2019b). Musoke et al's (2019b) findings further reinforce the need for a collaborative approach through engagement with various stakeholders.

There is no doubt that partnerships between national governments and external institutions such as NGOs have had a substantial influence on attaining good health outcomes in LICs (WHO 2016b). Specifically, in Uganda, the support from NGOs was instrumental in Uganda's success in addressing the HIV epidemic by providing access to ART (Muriisa and Jamil 2011; Whyte et al. 2013). However, there has also been negative impacts of their influence on national governance and coordination as indicated in the qualitative findings. In addition to their potential contribution to sustainability challenges with the CHWs programme, the qualitative data indicated that when NGOs fund health services in the country, they do so based on their own agenda and not necessarily in line with the government priorities (Mays et al. 2017; WHO 2016b). The implication is that the NGOs then perpetuate several diseases specific or what is otherwise known as selective or vertical health programmes across the African continent (Druetz 2018; WHO 2016b). Whyte et al. (2013) explain this from a lens of 'projectification' of health care services. That is, NGOs perpetuating a projectified landscape of health care services through investment in disparate projects which are not harmonised or necessarily linked to the national health agenda. This projectified landscape of care further perpetuates reliance on NGOs to support health service delivery through provision of funds for health programmes, albeit vertical. The study showed that a possible way to mitigate the reliance on NGOs is through an agreement, specifically a Memorandum of Understanding (MoU) to aid coordination between the Government and NGOs. In addition to having an MoU in place, there is also the need for mutual trust, transparency and open communication to build sustainable partnership (Musoke et al. 2016) between the government and NGOs. The establishment of an MoU agrees with the suggestion from a recent review which also highlights the importance of establishing an agreement between the NGO and government requiring the government to take responsibility for an aspect of the NGO's funded health programme (Nanyonjo et al. 2019). Therefore, any early breast cancer detection programme by an NGO should work closely with the government and be guided by an MoU to ensure a coordinated approach.

The reliance on NGOs can almost be said to be inevitable due to the failure of the national government to commit to funding local health initiatives. For instance, the previous chapter discusses how the inability of the Ministry of Health to provide funding for policy

implementation breeds reliance on NGOs to provide funding and other resources. This issue is similar across other countries in SSA, for instance, in order to fund the establishment of a cancer centre in Nigeria, Nwogu et al. (2016) approached the government to seek their commitment and support but this failed. Hence the project proponent had no other choice but to opt for private funding which was successfully secured (Nwogu et al. 2016). The consequence of inadequate or in some cases complete lack of government funding also reflects in the health service delivery fee as users pay out of pocket costs in order to access breast cancer services. A recent study conducted in Ghana showed that although the country has a national health insurance scheme which is supposed to cover access to all health services, this does not cater for the full costs of breast cancer treatment due to insufficient government funding, hence, individuals are required to pay (Agbokey et al. 2019). Out of pocket expenditure for health has been linked to the increasing rate of impoverishment in LICs (Jacobs et al. 2011). However, findings from this study clarify that poverty does not militate against early detection directly in the context of government health care delivery but rather has more effect on treatment. As discussed in the literature review, although Uganda provides free breast cancer treatment services, due to insufficient government funding the country experiences high drugs stock out, thus users are required to pay to purchase cancer drugs (McKenzie et al. 2016). This then poses a challenge of inability to access breast cancer detection services and because treatment is expensive, a woman may not be keen to detect breast cancer. The implication is that women may not be keen to utilise breast cancer detection services if they know that they would not be able to afford follow on treatment services if they so require it. This emphasises the importance of looking beyond breast cancer detection towards comprehensive breast cancer control, as discussed in section 7.5.3.

Poverty also engenders the commodification of health services at the PHC level. Although the situation analysis showed that individuals are not required to pay for government services at PHC centres, a respondent from the qualitative indicated that while that is the expected, it is not the same in practice. However, from the findings, it was evident that payment is not directly made to the government's purse but is sometimes required from PHC staff as a result of irregular payment of health workers salaries. Irregular payment of health workers as well as general poor working conditions have been documented as being a major challenge in SSA

and has been attributed as a driver of informal health payment (Onwujekwe et al. 2018; Lewis 2007; Ssali 2018). According to Onwujekwe et al. (2018) who compiled a working paper on corruption in West Africa, these informal payments are a form of corruption and they undermine the achievement of equity in PHC delivery. For instance, the commodification of health services may breed a lack of trust in health workers (Huang et al. 2018), thereby affecting the uptake of health services. This consequently undermines the attainment of the UHC agenda. The commodification of PHC service delivery as well as its consequences has been recognised as being rooted in poverty (Sachs 2012; WHO 2010a). This recognition links to the study participants indication of poverty as the mother of all other challenges. However, poverty itself and other breast cancer detection challenges are manifestations of an underlying driver of health: the political economy.

An understanding of the political economy of health provides a critical view of the underlying determinants of health service delivery. Specifically, political economy analyses the power relations that shape and drive global health inequities (Navarro 2009; Sparkes et al. 2019). For example, a recent critical analysis of inequity in breast cancer detection in Uganda through a structural violence lens posits that the influence of the prevailing neoliberal political economy is manifested through configurations of the global funding architecture which propagates weak PHC systems for breast cancer detection, and eventually manifests through poverty and various challenges at an individual level (Ikhile, Gibson and Wahidin 2019). A critical review of the history of the weak health system in Uganda also indicates a link to the prevailing political economy structures. According to Young (1993), when Uganda gained its independence in 1962, it was left 'deeply impoverished' by the 'colonial inheritance' just like many other countries in Africa and the Caribbean who became independent between 1945 and 1965. This resulted in a fragmented national economy, poor education infrastructure and weak health systems (Young 1993). It is therefore evident that the manifestation of weak PHC systems in Uganda has its roots in colonialism and the subsequent neoliberal political economy structure. Therefore, in order to truly strengthen and sustain health care delivery investments at the PHC there is a need to address this underlying structure. A recommended approach is provided by Navarro (2009) who prescribes a combination of national health policy focusing on participation, economic and

social determinants, environmental protection, favourable conditions throughout the life course, cultural determinants, and health promoting interventions.

Chapter Summary

This last chapter on the qualitative findings has presented and discussed the need for looking beyond breast cancer detection only, towards a comprehensive breast cancer control. It also discussed the perceived influence of health workers' gender in the delivery of early breast cancer detection services. In addition, the chapter provided findings around words used to describe women by the different participants. This chapter concluded by drawing out pertinent challenges that still exist in relation to breast cancer detection and control. The next chapter draws out the theoretical, practical and policy implications from the quantitative and qualitative findings of this study.

CHAPTER EIGHT

8.0 STUDY IMPLICATIONS

This chapter synthesises findings from the quantitative and qualitative phases to draw out practical, policy and theoretical implications from this study. The practical implications discuss what the findings mean in terms of strengthening the PHC capacity to deliver early breast cancer detection services in Kajjansi town council. It further discusses the potential translation of this approach to a national level and similar settings in Africa and other LICs. This chapter specifically presents the qualitative findings within a socioecological model and how they translate into a framework to inform future implementation.

8.1 Interpreting the Findings Using a Socioecological Lens

The literature review and situation analysis established that the challenges of early breast cancer detection are complex as indicated by an intricate web of interacting individual, community, structural, organisational and policy factors. Therefore, possible multi-level solutions identified from the qualitative data collection are also presented within the socioecological model.

8.1.1 Individual level

At an individual level, the study identified community wide breast health education (section 5.3.4) as a practical way of addressing breast cancer detection challenges that manifest at an individual level such as low knowledge, fear and misconceptions. Although various studies have indicated that while individual interventions dominate health promotion practice, they are limited in their capacity to effect robust changes as they do not consider the contextual variables that influence health outcomes (Fitzgibbon, Kong and Tussing-Humphreys 2014; Golden and Earp 2012). Still, for breast cancer detection and control in general, breast cancer education is ‘mandatory’ (Anderson et al. 2008, p. 2237) and a number of authors have called for setting up breast cancer education programmes for individuals as the first step to improving early breast cancer detection at the PHC level (Finkel 2018; Sayed et al. 2019; Sivaram et al. 2014). As indicated from the qualitative finding on taking a collaborative

approach (section 6.0), the target population for a breast cancer education programme should include both women and men.

8.1.2 Community level

Whereas the individual level intervention focused on service users, women and men, the proposed community level intervention is focused on capacity building of CHWs. As presented in the situation analysis (section 4.3.1), the PHC level comprises the health centres and the CHWs. Thus, building the capacities of the CHWs to better deliver breast cancer detection services within their communities (as discussed in section 5.3.4) is an integral pathway towards strengthening the PHC system. Both the quantitative and qualitative data establish the importance of CHWs to PHC delivery as well as promoting access to the community. Thus, they are well positioned to address the challenges of inadequate breast cancer organisations and curbing breast-cancer related stigma. The role of CHWs in this regard is to facilitate health promotion and education activities (Seutloali, Napoles and Bam 2018), similar to their established role from the situation analysis. Therefore, capacity building of the CHWs is crucial to delivering breast education programmes for individuals. Although capacity building of CHWs is situated within the community level, in practice, CHWs are uniquely positioned between the PHC system and community. Hence, they can be trained to promote breast cancer awareness at community level and also refer women to the necessary health centre as required. As indicated from the qualitative findings, the capacity building for CHWs should not only be based on breast cancer knowledge and skills, but also include soft skills such as counselling and professionalism. The components of the capacity building as identified from the qualitative study involve training of CHWs to enable them to educate women from an informed position, provision of mentorship and ongoing support, and provision of incentives for CHWs. The incentives identified include job aids, umbrellas, gum boots, t-shirts, rain boots and regular stipends. According to the CHWs, provision of these incentives does not only motivate them but also improves their standard of living, which makes the CHWs better able to serve their communities.

8.1.3 Structural level

At a structural level, a key finding from the study in relation to addressing distance and poverty challenges was in terms of delivering early breast cancer detection services at the community level through community outreach. As discussed in section 5.3.3, community outreach involves taking breast cancer detection services to the women in their natural settings as opposed to the women visiting the health centres. The study findings indicate that delivering breast cancer detection services through community outreach can take away the financial and time burden of travelling far distances to health centres or hospitals. Also, the qualitative findings on the perceived influence of the health workers' gender and the language used to describe women (Sections 7.5.1 and 7.5.2) call for an understanding of the social constructions of gender and women's identities in breast cancer care in Uganda. Breast cancer is one of the many diseases that could affect a woman at any point in her lifetime. Thus, to achieve optimal gain in women's health and wellbeing, there is a need for a holistic approach to meet the health needs of a woman as a person. This means health beyond treating a woman as a mother by focusing on maternal health, or as a wife in terms of sexual and reproductive health.

8.1.4 Organisational level

At the organisational level, the qualitative findings identified capacity building of PHC workers (section 5.3.4), establishing breast cancer clinics (5.3.2), integrating breast cancer detection with existing services (section 5.3.2) as practical solutions to address the challenges associated with weak PHC system. Although establishing breast cancer clinics would involve reorientation of the existing PHC system, the findings showed that integrated PHC service delivery is a cost-effective approach to synergise PHC efforts by integrating breast cancer detection services with services which have similar target population, that is women. Notable services identified from the quantitative and qualitative data collection to provide entry points for integration include maternal and child health, reproductive health, HIV and cervical cancer screening services. The integration of breast cancer detection services to the existing PHC system requires training of the PHC workers and careful planning through task allocations and having designated breast cancer clinic days to prevent overwhelming the already strained

PHC staff. Also, as highlighted from the qualitative findings (section 6.9.2), a stratified approach is recommended within the PHC centres level as depicted below (Figure 8.2). This stratified approach will only be effective if a strong referral mechanism is put in place to ensure timely referral from a lower level health centre to a high level.

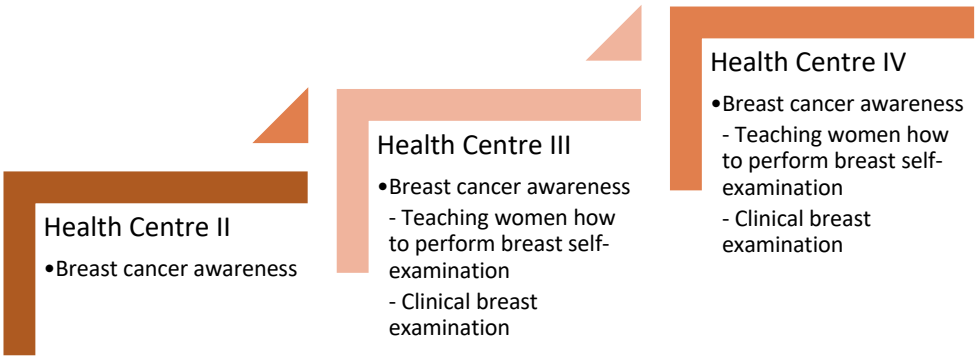

Figure 8.1: Stratification of breast cancer detection services at the PHC centres in Kajjansi town council

8.1.5 Policy level

At the policy level, the framework highlights the need to develop and implement an NCCP and a breast cancer guideline (section 5.3.4) in order to provide strategic direction into the provision of breast cancer detection services at the PHC level. It is important to develop policies that emphasise PHC as well as develop a complementary breast cancer guideline as is the case with the Zambian NCCP (Cabanes et al. 2019). Therefore, the recommended solution within this level requires the Ugandan national government to invest in the development of an NCCP as well as a separate guideline for breast cancer as the government did in the case of putting in place a strategic plan for cervical cancer (Ministry of Health 2010c). The expectation is that having a stand-alone breast cancer guideline would drive the prioritisation of a preventative approach and sustained delivery of early breast cancer detection services at the PHC level, not just investing in breast cancer treatment. In addition, the study identified effective allocation and administration of funds to implement the suggested solutions and sustain early breast cancer detection efforts.

These solutions are summarised in Figure 8.2:

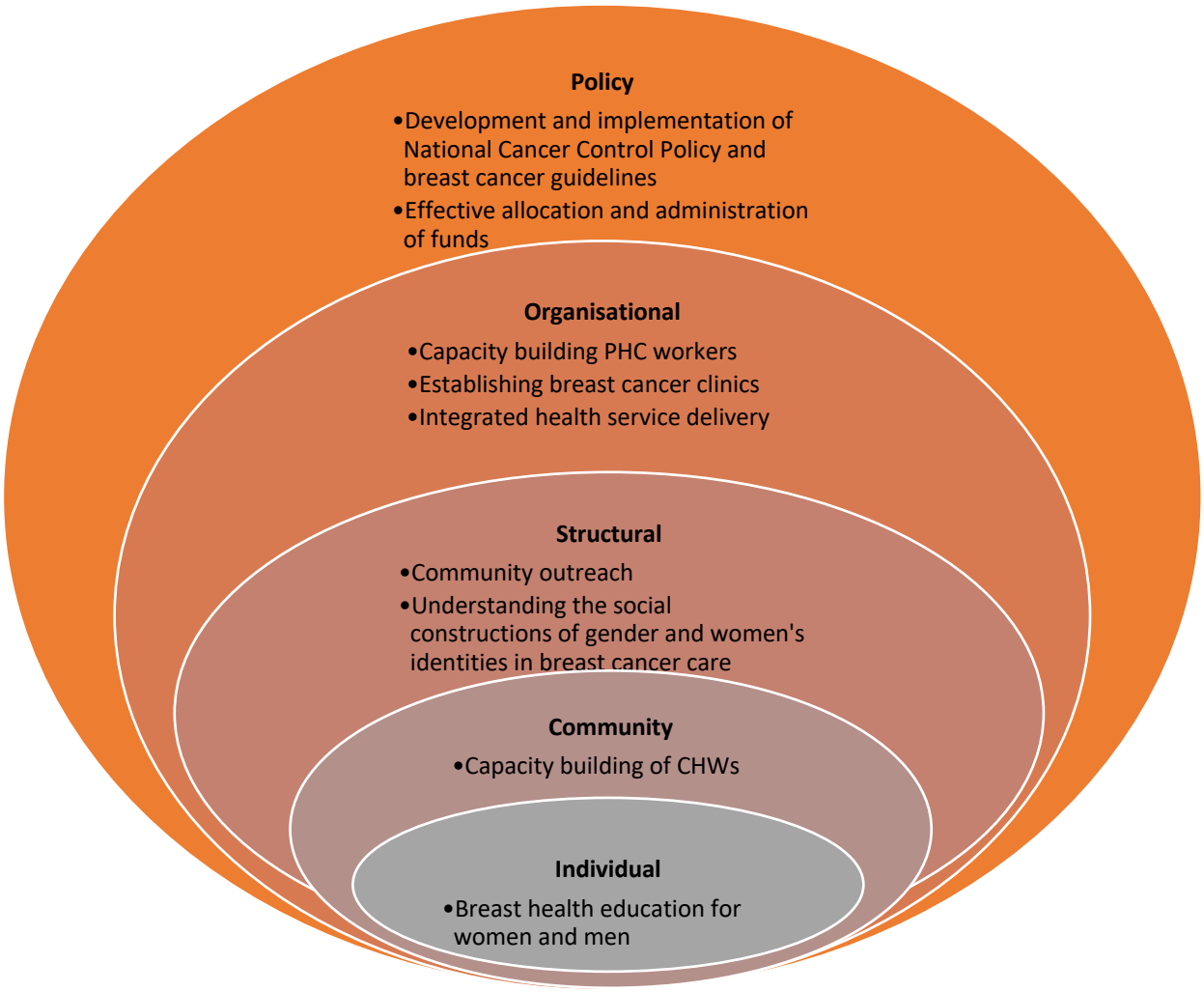

Figure 8.2: A socioecological model showing solutions to promote early breast cancer detection

8.2 Towards a Breast Cancer Detection Framework

Effective strengthening of the PHC system for improved breast cancer control requires a recognition of breast cancer detection as a multi-level issue. As stated by Schettler (2013) in their book which focuses on the ecology of breast cancer, "we will undoubtedly be more successful at…promoting [breast cancer detection] if we approach it through multi-level interventions. Individuals cannot do this alone" (p. 3). The recognition and need for this multi-level approach have been established from this study to inform the development of 'A Breast Cancer Detection' Framework (ABCD Framework). The ABCD framework is an integrated framework which situates breast cancer detection within an expanded socioecological model. This integrated framework combines the solutions presented within the socioecological

model in section 8.1 as well as components of a logic model to provide a clear and defined pathway required for implementation. Therefore, the ABCD framework serves as a conceptual framework which does only highlight interventions but draws on logical steps (based on logic model) that highlights multiple levels of influence; inputs; activities; outputs; outcomes; impact; and underpinning principles (Figure 8.2) required to achieve the desired impacts of a strengthened PHC to deliver culturally appropriate early breast cancer detection services. The need for a culturally appropriate approach for implementing a breast cancer detection programme is highly encouraged (Anderson, Ilbawi and El Saghir 2015; Cabanes et al. 2019) due to contextual differences in breast cancer across countries. The ABCD framework posits that a strengthened PHC system for improved early breast cancer detection can be achieved through one or a combination of the following interventions based on the solutions presented in the socioecological framework (Figure 8.2):

1. Individual level intervention: Breast cancer education for women and men
2. Community level intervention: Capacity building of CHWs
3. Structural level intervention: Community outreach; Understanding the social constructions of gender and women's identities in breast cancer care
4. Organisational level interventions: Integrated PHC delivery; Capacity building of PHC workers; Establishing breast cancer clinics
5. Policy level intervention: Development and implementation of National Cancer Control Policy and breast cancer guideline

The solution around understanding the social construction of gender and women's identities in relation to breast cancer care informed the principle of gendered approach discussed in section 8.2.1. The five possible interventions build on Sivaram et al.'s (2014) recommendation to focus on community-based or health systems research in order to put in place a cancer control programme. However, this study builds on their recommendations by adding 3 more layers: individual, structural and policy level interventions. Although De Leeuw, Clavier and Breton (2014) and Sivaram et al. (2014) argue that policy is not an intervention but a resource which drives implementation of an intervention, the combined development and implementation of a cancer control policy and breast cancer guideline is considered an intervention in its own right.

Figure 8.3: ABCD framework for strengthening the PHC for early breast cancer detection

Underpinning Principles
Community based resources
Collaborative approach
Gendered approach

LEVEL OF FOCUS	INPUTS (RESOURCES)	ACTIVITIES	OUTPUT	OUTCOME
POLICY	▪ Political commitment ▪ Funding	▪ Develop NCCP and breast cancer control guidelines ▪ Effective allocation and administration of funds policy implementation	▪ Established NCCP and breast cancer control guidelines ▪ Adequate funds available for policy implementation	▪ Strategic guidance on delivery of breast cancer detection services at PHC level ▪ Implementation of breast cancer control guidelines
ORGANISATIONAL	▪ Established breast cancer control policies/guidelines ▪ Funding ▪ Motivation packages	▪ Integrated PHC service delivery ▪ Scheduled breast cancer clinics ▪ Training of health workers	▪ Knowledgeable health workers ▪ Routine CBE services	▪ Implementation of breast cancer control policies/guidelines ▪ Improved availability of breast cancer detection services ▪ Timely referral for early diagnosis
STRUCTURAL	▪ Funding ▪ Knowledgeable PHC workers ▪ Community based multimedia resources	▪ Community outreach ▪ Understanding the social constructions of gender and women's identities in breast cancer care	▪ Accessible and contextually appropriate early breast cancer detection services	▪ Equitable access to early breast cancer detections services for all women at a PHC level
COMMUNITY	▪ Funding ▪ Knowledgeable health workers ▪ Incentives for CHWs ▪ Community based multimedia resources	▪ Capacity building for CHWs ▪ Provision of financial and non-financial incentives ▪ Training of CHWs	▪ Strengthened capacity of CHWs to promote breast cancer detection through community wide breast health education	▪ Increased accessibility to breast cancer detection services for women ▪ Timely referral to PHC centres for suspected breast cancer cases
INDIVIDUAL	▪ Time commitment (from women) ▪ Community based multimedia resources ▪ Knowledgeable PHC workers	▪ Breast health education	▪ Knowledge and practice of early breast cancer detection strategies	▪ Individual/community empowerment around breast cancer control ▪ Improved health seeking behaviour

IMPACT

Strengthened PHC capacity for breast cancer detection

● Available breast cancer detection services at the PHC centres ●Early detection of breast cancer by women and PHC workers ●Early presentation of breast cancer at PHC ●Early presentation of breast cancer at PHC ●Structural barriers are mitigated (distance, sex of health workers financial constraints) ●Early referral for follow-on diagnostic and treatment services

Although the proposed framework presents a multi-level approach to promoting breast cancer detection, focused interventions can also be implemented at the specific levels. However, it is important to note that while intervening at specific levels may be implemented as low hanging fruits, lasting and effective impacts can only be achieved when all these levels are considered holistically, through a health promotion approach. Health promotion is "the process of enabling people to increase control over, and to improve, their health" (WHO 1986, np.). Based on this definition, health promotion is an enabling process which facilitates the implementation of the four previously discussed interventions. This emphasises the position of existing literature that health promotion is a multi-level approach (Golden and Earp 2012; Seutloali, Napoles and Bam 2018). Although more complex than intervening at specific levels, this is more likely to yield robust results than single level interventions. Hence, this study calls for such a health promotion approach in the early detection of breast cancer.

8.2.1 Principles of a culturally appropriate early detection programme for breast Cancer

Three core principles are proposed based on the study findings to underpin the implementation of the ABCD framework:

1. Gendered approach
2. Collaborative approach
3. Community-based resources

Gendered approach

The purpose of promoting early breast cancer detection is to promote equitable access for women. As indicated by the study findings, this requires a gendered approach due to the social constructions of sex of health worker and women's identities in relation to breast cancer care. Such gendered involves understanding the power relations in the delivery of early breast cancer detection services, sensitising CHWs and other PHC workers on gender constructions and taking a relational perspective. As established from the qualitative findings, gendered approach also requires professionalism, cultural appropriateness and context specificity. Taking a gendered approach is linked to providing holistic care which takes a shift from selective to comprehensive PHC delivery. A gendered approach presents a way of empowering women to become active stakeholders in breast health delivery and ensuring

that their needs are properly articulated in shaping health agendas. Thus, promoting equity in access to health services. There has been a recognition of the importance of taking a gendered approach as evidenced by the calls and actions for gender to be mainstreamed in policy and practice in what has become popularly known as gender mainstreaming (Hawkes, Buse and Kapilashrami 2017). However, gender mainstreaming has been criticised for its lack of criticality and disconnect from feminist theories, hence there is a recent call for gendered approach to be underpinned by feminist theories (Tolhurst et al. 2012). On the other hand, gender does not operate in isolation, so, in addition to taking feminist perspectives, there is a need to understand how gender intersects with other social stratifiers such as religion. An approach for this is what has become recently known as intersectionality in health services research (Bauer 2014; Kapilashrami and Hankivsky 2018; Tolhurst et al. 2012). According to Kapilashrami and Hankivsky (2018), an intersectionality lens is integral to analyse how gender intersects with other social stratifiers towards attainment of the SDG goal 3 of leaving no one behind. This is important to understand how gender intersects with social stratifers like religious beliefs and how this impedes access to breast cancer detection services, particularly when such services are delivered by male health workers.

Collaborative approach

Coordination of interventions within and across the different levels require collaborative action through community participation and engagement with stakeholders from other sectors. For instance, the NGOs and Ministry of Health can only provide services that adequately respond to the needs of the community if they co-produce solutions with the community level stakeholders. Furthermore, when the government engages with NGOs, they are able to coordinate their activities better in order to avoid duplication of efforts which is the prevailing practice. Community participation is also important to ensure that services made available are effectively utilised by the women. From the qualitative findings, it was evident that the concept of health for all in relation to breast cancer detection places the responsibility for health for all on a wide range of stakeholders. This understanding is important to challenge the medical and biomedical perspectives which victimise women and places the responsibility for health solely on them.

Community based resources

The study highlighted a wealth of community-based multimedia resources which can be utilised to create breast cancer awareness and even offer demonstration exercise for BSE or CBE for women such as film vans which have been utilised as mobile breast examination units in Brazil (Filho et al. 2014). At a high level, the availability and adequate allocation of resources are crucial to the implementation of the ABCD framework. The training of PHC workers, capacity building of CHWs and breast health education interventions are not possible without the procurement or allocation of required resources such as IEC materials to teach women, training materials for PHC workers and provision of motivational incentives. These resources require funding which can either be obtained from the government or through NGOs. Another community-based resource is the existing knowledge. Specifically, design of training curriculum and health promotion materials should be informed through local expertise from multidisciplinary stakeholders ranging from clinical, surgical and PHC practitioners.

8.2.2 Feasibility and limitations of the ABCD framework

The ABCD framework is proposed as an implementation framework for strengthening the PHC to deliver early breast cancer detection in Uganda. It is also important to highlight that the ABCD framework recognises strengthening PHC as both a process and an outcome, that is the different components encompass strengthening the PHC as highlighted from the study findings. However, the resultant impact is a strengthened PHC system capable of catalysing improved early breast cancer detection. Also noteworthy is that early breast cancer detection is only effective when there is access to follow on breast cancer control services (Finkel 2018; Sivaram et al. 2014). That is why increased breast cancer survival is not included in the framework. The premise of the framework is not based on a one size fits all approach. The feasibility of implementing the frameworks needs to be determined through consensus-building with stakeholders to ensure its fit for purpose and context. There is therefore the need for feasibility studies to evaluate the readiness and capacity of the PHC system to carry out the recommended interventions. Also, even though findings from this study suggest that putting in place an early breast cancer programme within the existing PHC system is neither an impossible nor hugely expensive venture, the effective translation of the framework into practice will require engagement with the field of implementation science.

Limitations of the ABCD framework

The main limitation of the ABCD framework is that it only covers breast cancer detection continuum, which on its own is insufficient to reduce breast cancer mortality. Hence, increased breast cancer survival is not included as an impact because that would depend on the availability of follow-on diagnostic and treatment services. Also, as the qualitative findings have shown (section 7.4), challenges remain in relation to reliance and subsequent influence of NGOs, overburdening CHWs, shortage of PHC workers, commodification of health care and poverty. These challenges could impede the effective implementation of the ABCD framework and sustainability of outcomes if they are not addressed. A recommended starting point is the acknowledgement and prioritisation of breast cancer as a critical national health issue. This can then drive high level commitment and prompt effective resource allocation for breast cancer control that looks beyond investment in treatment infrastructure.

8.3 Contributions to Knowledge and Practice

The findings from this study have shown that the knowledge of various approaches to disease management exist within the PHC system. What is lacking which is the novel contribution of this research is how to synthesise, adapt and translate this knowledge to breast cancer detection practice. The synthesis of this study findings into the ABCD framework is an original contribution of this study. So far, there is limited study on how the PHC can deliver early breast cancer detection services for in women in Uganda. Hence the situation analysis contributes to knowledge by providing evidence of PHC capacity to provide breast cancer detection in Kajjansi town council, Uganda. The situation analysis findings can also inform policy as it highlights the gap in breast cancer detection services at the PHC level. Findings from the qualitative research further showed that addressing the challenges of breast cancer detection would contribute towards strengthening the PHC capacity. However, strengthening the PHC capacity goes beyond addressing the challenges of breast cancer detection but also encompasses practical considerations of resources required and involvement of different stakeholders. In terms of the practical application of knowledge, there is a potential to implement the ABCD framework in Kajjansi town council and expand to other cancers or start with the town council and roll out to other town councils across the district.

For countries with tiered health systems similar to Uganda such as Tanzania (The United Republic of Tanzania, Susan G Komen and Breast Cancer Initiative 2. 5 2017), the approach proposed from this study could be adapted to fit the country's context in the provision of early detection services for breast cancer or other cancers. It should be noted that there is no one size fits it all for breast cancer control. That is, early detection strategies for breast cancer would vary within and across countries depending on resource availability. Shetty (2014b) points out that urban-rural dynamics would have an impact on breast cancer control because urban populations may have access to higher quality cancer care than rural populations. This difference includes better access to and use of mass media and social media in urban areas, higher literacy level, better access to health services and higher income status which mean women might be able to afford private health services. There is therefore a need for a comparative study to show the difference in implementing a breast cancer detection programme between an urban and rural setting.

8.3.1 Policy Contributions: implications for global health policy and practice

The global is inherently local (Labonte 2008), thus, any progress made at the local and national levels will inadvertently contribute towards global efforts. Hence, findings from this study have the potential to influence global policy and practice. There is an increasing interest in promoting access to PHC services in SSA as evidenced through global health commitments to UHC. Strengthening the PHC system has been identified and reiterated in the Astana Declaration (WHO 2018a), hence the approach proposed in the study has global implication of contributing towards achieving the UHC and health for all agenda.

8.3.2 Theoretical contribution: value of a socioecological framework for public health practice and research

It is insufficient to plan a research on making recommendations for policy and practice without applying a theoretical framework on which the research or practice will be grounded upon (Glanz, Rimer and Viswanath 2008). As a result, a number of authors have called for an alternative approach to doing public health. For instance, Earle (2007) asserts that contemporary public health requires joint efforts across all levels of influence, from individual behaviours through community actions and national and international policies. Individual

theories in themselves are insufficient in explaining the full depth and significance of health promotion. In his book on health and modernity, McQueen et al. (2007) succinctly enunciates the need and importance of theory for health promotion. According to him, the use of theory does two main things, first as a move towards holism and secondly to provide a boundary to health promotion practice such that the strive for holism does not result in unrealistic pursuits for the entire realities of life.

Different frameworks have been designed for breast cancer detection. For example, Pace et al.'s (2018) algorithm for the management of breast concerns among breastfeeding and non-breastfeeding women. Although the algorithm made a useful distinction in breast cancer detection for breastfeeding and non-breast-feeding women, it was focused on individuals only (women). The WHO *Package of Essential Non-communicable Diseases Interventions for Primary Health Care* also offers technical guidance on the minimum standard how PHC systems can be strengthened through integration of NCDs services (WHO 2010b), but a recent publication has shown that gaps still exist in terms of evidence-base on how this integrated approach can be implemented (Dodd et al. 2019). Furthermore, the WHO *Package of Essential Non-communicable Diseases Interventions for Primary Health Care* only applies to countries which have adopted a national policy framework on NCDs prevention and control (WHO 2010b). The use of a socioecological model in cancer management underpins the United States national organised Breast and Cervical Cancer Early Detection Program (Centres for Disease Control, and Prevention 2013). However, this programme does not provide clarity on how the socioecological model guides its implementation process. Although some studies have recommended the use of a socioecological approach for breast cancer detection (Al-Moundhri 2013; Ilaboya, Gibson and Musoke 2018), this is the first known study to provide such framework in the Ugandan context not only from a multi-level stance but also with a clear guidance for implementation.

8.3.3 Methodological Contribution

The use of mixed methodology added value to this study in the sense that the quantitative and qualitative data provided robust understanding of early breast cancer detection within the study setting. Also, this study is the first known study to use a sequential explanatory MMR design for early breast cancer detection research in SSA. The clear discussion provided

around the choice of my underpinning paradigm, pragmatism, is another methodological contribution as there is limited evidence on the use of pragmatism to guide MMR on breast cancer detection. Existing studies which have used MMR (Bonsu and Ncama 2019; Kohler 2015; Sayed et al. 2019) did not indicate the paradigm. The use of Skype is also a major methodological contribution from this study, especially when faced with uncertainties such as personal challenges, logistics constraints or global health pandemic such as the COVID-19 pandemic which makes it impossible for researchers to travel for data collection. A detailed description of my experience conducting the Skype interviews has been submitted to a journal for publication. Another methodological contribution is the clarity provided on choice of the paradigm, pragmatism underpinning the MMR design for this study.

8.4 Next Steps

The next step is to take a co-production approach to engage with different stakeholders in order to implement one on more of the interventions presented above through an implementation science approach. The significance of this is "implementation science comes into play after evidence is gathered" (Sivaram et al. 2014, p. 13). The evidence to promote the early detection of breast cancer in Uganda has been gathered from this mixed methodology study, hence, the next logical step is to translate the evidence into practice. The second step is to contribute to the existing body of knowledge through dissemination. Although some dissemination activities have been undertaken as part of this study (see List of Outputs), more are planned to target various stakeholder categories as outlined in the dissemination plan in Table 8.1 below:

Table 8.1: Proposed dissemination plan for different stakeholders

Stakeholder	Dissemination strategy
Community/women	Language appropriate infographic posters, community talks for women groups and CHWs
Health workers	Mini reports
Ministry of Health	Policy recommendations
Academic community and other researchers	Peer reviewed articles, conference presentations, seminar presentations and blogs

CHAPTER NINE

9.0 CONCLUSIONS AND RECOMMENDATIONS

Breast cancer is usually detected late among women in Uganda for various and complex reasons ranging from low knowledge of a woman, community challenges such as stigma, weak PHC capacity for breast cancer detection, distance and sex of health workers, and lack of national cancer policy. In spite of the key role played by PHC in health promotion, diseases prevention and management, there is an identified gap in the delivery of early breast cancer detection services at PHC level in Kajjansi town council as well as other parts of Uganda. Therefore, this study aimed to critically examine how the primary health care capacity in Kajjansi town council can be strengthened to deliver early breast cancer detection services for women. Particular focus was on developing practicable strategies to address the challenges of breast cancer detection at a PHC level. In addition, the study aimed to further explore the implications of the insights generated for policy and practice relating to the early detection of breast cancer. Due to the complexity and multiplicity of breast cancer detection challenges, a socioecological model was used to provide a multi-level understanding and to analyse the interactions between the different challenges. The methodology for this study was based on a sequential explanatory mixed methodology research design which comprised of two phases: phase 1 (quantitative phase) and phase 2 (qualitative phase).

This thesis concludes by summarising how the study has answered each of its stated questions which are:

1. What is the existing PHC capacity for early breast cancer detection in Kajjansi town council?
2. What practical solutions can be used to address the challenges of early breast cancer detection in Kajjansi town council?
3. How can these solutions improve the PHC capacity to deliver culturally appropriate and context-specific early breast cancer detection services in Kajjansi town council?
4. What are the implications of the findings for local and global breast cancer detection policies and practices?

What is the existing PHC capacity for early breast cancer detection in Kajjansi town council?

A situation analysis was conducted during the quantitative phase to evaluate the availability of early detection services for breast cancer in Kajjansi town council. This was important as no study has been previously conducted in relation to this. The situation analysis was conducted through health centre assessments of the existing government-funded PHC centres (n=3) in the project area and an assessment with community health workers (CHWs) which involved 292 participants. The situation analysis established that early detection services for breast cancer are limited at the PHC level and provided by NGOs, thereby contributing to accessibility challenges for women. Although none of the CHWs offered any early breast cancer detection services, the findings showed that they are integral to health promotion. In addition, key challenges to early detection services included funding challenges and inadequate training. On the other hand, key opportunities for promoting early detection of breast cancer were identified through leveraging on existing services and building the capacities of CHWs.

What practical solutions can be used to address the challenges of early breast cancer detection in Kajjansi town council?

The qualitative phase provided deeper insights on the quantitative findings focusing on the 'what and how'. In terms of 'what', the qualitative data collection phase provided practical solutions on how the challenges can be addressed. It further provided evidence on how the solutions and opportunities identified in the quantitative phase can be implemented. The qualitative phase indicated that strengthening the PHC capacity for early breast cancer detection is both a process and an outcome. Findings from the qualitative research further showed that addressing the challenges of breast cancer detection would contribute towards strengthening the PHC capacity. However, strengthening the PHC capacity goes beyond addressing the challenges of breast cancer detection but also encompasses practical considerations of resources and involvement of multi-sectoral stakeholders.

How can these solutions improve the PHC capacity to deliver culturally appropriate and context-specific early breast cancer detection programme in Kajjansi town council?

The outcome of this study is 'A Breast Cancer Detection Framework' (ABCD) framework which provides a culturally appropriate approach on how the PHC capacity can be strengthened to deliver early detection services for breast cancer in Kajjansi town Council. The framework is based on an integration of the socioecological model and logic model in order to provide a clear pathway for translating the study findings into practical outcomes towards strengthening the PHC capacity for improved breast cancer detection. The ABCD framework proposes five interventions based on the multi-level solutions presented within a socioecological model:

- Policy level: Development and implementation of National Cancer Control Policy and breast cancer guideline
- Organisation level: Integrated PHC delivery; Capacity building of PHC workers; Establishing breast cancer clinics
- Structural level: Community outreach; Understanding the social constructions of gender and women's identities in breast cancer care
- Community level: Capacity building of CHWs
- Individual level: Breast cancer education for women and men

All these interventions combined make up a multi-level intervention which can be achieved by taking a health promotion approach. Interventions can be delivered holistically through a multi-level lens or singly as part of a whole. However, a multilevel approach is recommended for coordinated and sustainable impacts.

What are the implications of findings for local and global breast cancer control policies and practices?

Findings from this study have shown that putting in place a breast cancer programme within the current existing PHC system is neither an impossible nor a hugely expensive venture. Therefore, the evidence generated has strong implications for PHC practice around breast

cancer detection service delivery. The ABCD framework provides a practical approach and a useful starting point for translating existing knowledge of PHC delivery to promote early detection for breast cancer. Although the proposed framework is specific to Kajjansi town council, its components can be adapted to fit similar settings in Uganda and across SSA at large especially for settings with tiered health care system similar to that of Uganda. Since the local is also inherently global, the impacts of this study findings at a community level have the potential to inform the approaches to breast cancer detection nationally and in other countries. However, the effectiveness of the proposed framework will be influenced by contextual factors.

9.1 Recommended Areas for Future Research

Research priorities recommended from this study are highlighted below:

- *Implementation study:* The first and perhaps most immediate recommendation from this study is the need for an implementation study to focus on some (as low hanging fruits) or all the highlighted interventions towards strengthening the PHC system for improved early breast cancer detection.
- *Feasibility studies:* to be carried out to evaluate the readiness and capacity of the different health centre levels to carry out the recommended interventions. To ensure alignment with global efforts, the WHO *Package of Essential Non-communicable Diseases Interventions for Primary Health Care* should be used to guide such feasibility studies.
- *Investment in comprehensive breast cancer control*: Breast cancer is a complex health issue as seen from the intricacies surrounding the different spectrums of the breast cancer continuum. These intricacies emphasise that all spectrums need to be harmonised for effective breast cancer control, and while early detection is important for breast cancer control, it would be ineffective without diagnostic and treatment facilities or palliative and survivorship care where appropriate. Therefore, there is a need for the Ugandan government to invest in comprehensive efforts in order to improve overall breast cancer survival in the country.

- *Strong referral and follow-up mechanisms:* The referral pathway is also integral for breast cancer. Therefore, further research is required on how this can be strengthened to ensure referred cases receive timely diagnosis and treatment. Further studies are particularly required to understand the referral pathway between regional and national hospitals and PHC centres. An appointment-based system of referral can be implemented to reduce delays and waiting time.
- *Intersectionality lens to gendered approach in breast cancer detection*: This study established that indeed a gendered approach is required to effectively deliver breast cancer detection services that are sensitive to the needs of women, the study also study found that gender intersects with other social stratifiers, notably religion and socioeconomic status. Hence, there is the need for further studies to explore and understand how these intersections (as well as intersections with other social stratifiers not included in this study) influence access to breast cancer control services in general.
- *Research from a feminist perspective:* One of the main shortcomings of a gendered approach is the lack of a theoretical framework to provide critical analysis of power relations between different groups. Therefore, further studies should employ a feminist perspective to provide a critical understanding of the power relations between men and women, especially as it pertains to breast cancer in women living in Africa.
- Further studies are also required to review the differential roles of male and female health workers in order to establish how their sexinfluences their performance. A participatory study involving women in the community and health workers would be useful to analyse the roots of the issues around the social constructions of sex of health workers and health-seeking behaviours.
- *Mixed methods situation analysis*: The situation analysis was conducted using quantitative surveys only. Future studies endeavouring to assess the infrastructure and capacities of health centres should consider observational and ethnographic style studies which would require the researcher to spend substantial time at each health centre to observe and verify reported cases and provide sufficient time to query discrepancies in reported and publicly available information.

- *Comparative study*: Due to urban-rural dynamics and differences in access to health care, there is a need for a comparative study to test the implementation and application of the ABCD framework in rural and urban settings.

REFLECTION

As I complete my thesis in the period of COVID-19, fraught with uncertainty, I can't stop thinking about how COVID-19 affects research and also reflect on the lessons I have learnt as an individual. Lessons that I find useful for breast cancer control practice as well as health promotion generally. Hence, I have focused my reflection on two parts: reflections on COVID-19 and its impacts on research and secondly reflections on my PhD research process.

Health for 'all' in practice

Never in my life have I witnessed such global action, community commitment and high-level individual compliance combined to address one health issue. Not even in the case of the Ebola epidemic. Reflecting on the collaborative efforts geared towards COVID-19 has made me better understand the meaning and practical implication of health for all. Health for all truly means all parties are taking responsibilities and actions to ensure all are safe. Generally, health has always been approached with NIMBYISM (Not-in-my-backyard attitude) but not in the case of COVID-19 as it ended up in everyone's backyard. We shouldn't wait until a health issue gets into 'our backyard' to take actions. When COVID-19 first emerged in China in December 2019, the world watched from a distance with the usual NIMBYISM, until it crept in on all, becoming a global pandemic in less than six months. Suddenly everybody was talking about it. The governments around the world were taking drastic actions, and [most] people were complying!

If only that could be the case with breast cancer and other diseases. If only there were no disparities if only breast cancer was indeed an issue of health for all…It is not impossible as shown from my research findings and what we now see as collaborative efforts towards surviving the COVID-19 pandemic.

Shifting away from research traditions

Even though I made the decision to transition from face to face to skype interviews due to personal and logistics constraints, a part of me still felt using Skype was not good enough and wondered what if. Of course, the resistance to Skype as a less rigorous form of data collection did not help matters. Now, with the COVID-19 situation and researchers being unable to

collect face to face data, the question that keeps coming to mind is should that put research to a halt? Certainly not! In fact, there is a renewed interest in online interviewing approaches now. The world is indeed changing, and we can no longer be boxed into a traditional way of doing research. Online interviewing skills should be regarded as core skills in this rapidly changing world.

What is the impact of my PhD? How would I evaluate the success of my research?

One the 7th of July 2016, my mentor who works at WHO asked me an important question: how would you evaluate the success of your research? I didn't have a response then but over the course of my PhD, and certainly, at this point of completion, the success of my research is defined by who I have become, what I have achieved and what I will achieve.

Who I have become:

After four years of my PhD journey, I can confidently say that I have become:

1. A pragmatist: Through this PhD, I have been able to position myself and better understand my worldview- I started out thinking I was an idealist but concluded as a pragmatist.
2. A knowledge expert in breast cancer detection: This study has enhanced my knowledge base and given me a better understanding of implementing breast cancer detection programmes as well as breast cancer management in general.
3. A resilient researcher: This PhD has also enhanced my ability to conduct academic research and navigate through the complexities and practicalities of external social factors outside academia. This process has built my resilience as I have gained the important skills of learning, unlearning and relearning in order to remain relevant as a contemporary researcher.

What I have achieved:

- The Barbara Rosenblum Breast Cancer Dissertation Award from the Sociologists for Women in Society: Getting this award for me was a strong indication that my research 'made sense'. That a group of an external panel who had never met me

would read through my research and find that it is unique because of its potential to inform practice- a point that was highlighted as lacking in most PhD research. This feedback made me keener to ensure my PhD has a strong application for practice.

What I will achieve:

Most importantly, the impact of my PhD is defined by the impacts it will achieve. Being able to raise awareness of the signs and symptoms of breast cancer and the need to seek timely care is a significant impact that this research could have especially for women living in remote communities in Uganda as well as other parts of Africa.

Concluding statement

In my quest for new knowledge, I have learnt that there is no 'new' knowledge, there is only existing knowledge which we just have to find. What I found out from this PhD is that though knowledge exists, what is lacking, which is the novel contribution from my PhD is the identification of this existing knowledge as being relevant and wisdom to translate this knowledge into practice.

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APPENDIX

Appendix 3.1: Health Centre Assessment Questionnaire

IDENTIFIER: _____

HEALTH FACILITY: _____

DATE: _ _/ _ _/ _ _ _ _ **(dd/mm/yyyy)**

HOW MANY INDIVIDUALS COMPLETED THIS SURVEY? _ _

1. FACILITY: OVERVIEW

1.1 WHAT BEST DESCRIBES YOUR FACILITY (PLEASE SELECT ONLY ONE OPTION)	SELECT ONE
A. **Primary care facility** – provides primary health care to patients who come to the facility with any undiagnosed symptom, or health concern. The services provided at the primary care facility do not have distinct specialties.	( )
B. **Provincial or Secondary-level hospital** – highly differentiated by function with five to ten clinical specialties, including internal medicine, obstetrics, gynecology, pediatrics and general surgery.	( )
C. **Tertiary-level hospital** - highly specialized staff and technical equipment. Clinical services are highly differentiated by function; might have teaching activities.	( )
D. **Cancer care/breast care facility**- specialized in cancer or breast cancer diagnosis and treatment.	( )
E. **Palliative care facility** – provides medical care that focuses on reducing the severity of disease symptoms, rather than a cure or reverse progression of the disease itself. The goal is to prevent and relieve suffering and to improve quality of life for cancer patients.	( )

1.2 WHAT IS THE MAIN SOURCE OF FUNDING FOR YOUR FACILITY?	SELECT ONE
A. Public - Government funded	( )
B. Private (for profit) – No government funding	( )
C. Mixed – Government and private funding	( )
D. Not-for-profit	( )
E. Mission/faith-based	( )
F. Foreign aid	( )
G. Other (specify):	( )

1.3 CATCHMENT POPULATION	NUMBER	DON'T KNOW
A. What is the estimated population of the catchment area served by this facility?		( )
B. Estimated number of women (15-65+) living in this catchment area?		( )
C. In a typical month, approximately how many patients visit your health facility?		( )
D. What estimated percentage of this population is female?		( )
Approximately what percentage of your female patients is:		
E. 0 – 19 years old		( )
F. 20 – 39 years old		( )

G. 40 – 64 years old		( )
H. 65 and above		( )
I. What is the average number of women attending your facility per month for breast health concerns?		( )

1.4 WHICH PERCENTAGE BEST DESCRIBES WOMEN WHO ATTEND YOUR FACILITY FOR BREAST HEALTH CONCERNS <u>WHO HAVE SYMPTOMS</u> OF BREAST CANCER? *Symptoms might include palpable lumps with or without palpable nodes, or other visible signs and symptoms of breast cancer.*	**SELECT ONE**	**DON'T KNOW**
A. Less than 50% of women (<50%)	( )	( )
B. Between 50% and 75% of women (>50% - <75%)	( )	
C. Between 75% and 90% of women (>75%- 90%)	( )	
D. More than 90% of women (>90%)	( )	
E. What **estimated percentage** of women with suspicious findings do not return after their initial consultation?	____ %	( )

1.5 INFRASTRUCTURE		
A. How many beds are in the facility?	**NUMBER**	**DON'T KNOW**
		( )
B. Do you have electricity in the facility?	**YES**	**NO**
	( )	( )
*If **YES**, what is the primary source of electricity?*		**DON'T KNOW**
C. Power grid	( )	( )
D. Generator	( )	
E. Other (specify):	( )	
F. Does this facility have water for functions such as hand washing for patient and staff use?	**YES**	**NO**
	( )	( )
*If **YES**, what is the primary source of water?*		**DON'T KNOW**
G. Borehole	( )	( )
H. Piped water	( )	( )
I. Rain water harvesting	( )	( )
J. Other (specify):	( )	

1.6 DOES YOUR FACILITY HAVE THE FOLLOWING:	YES (IN STOCK)	YES (OUT OF STOCK)	NO
A. Disinfectant	( )	( )	( )
B. Alcohol hand rub	( )	( )	( )
C. Paper towels or hand dryers	( )	( )	( )
D. Single use syringes	( )	( )	( )
E. Gloves	( )	( )	( )
F. Medical masks	( )	( )	( )
G. Gown	( )	( )	( )

1.7 DO YOU HAVE PARTNERSHIPS WITH ANY ORGANISATIONS THAT HELP IMPROVE THE DELIVERY OF BREAST HEALTH CARE?	SELECT ALL THAT APPLY	LIST PARTNERS WHERE APPROPRIATE
A. Cancer support/advocacy groups	( )	
B. Religious groups	( )	
C. National Foundations/organizations	( )	
D. National Universities/educational or research facility	( )	
E. Other domestic health facility	( )	
F. Industry	( )	
G. Foreign governments	( )	
H. Foreign (non-National) Universities/educational or research facility	( )	
I. International organizations	( )	
J. Other (specify):	( )	

2. EARLY DETECTION

PLEASE SELECT THE MOST APPROPRIATE RESPONSE FROM THE FOLLOWING 3 QUESTIONS

THERE ARE NO DETECTION SERVICES AVAILABLE AT MY FACILITY **(*SKIP TO SECTION 3)*** ☐

THESE SERVICES ARE AVAILABLE, BUT I DON'T KNOW ENOUGH ABOUT BREAST CANCER DETECTION **AT MY FACILITY** TO RESPOND ACCURATELY TO THESE QUESTIONS **(*SKIP TO SECTION 3)*** ☐

THESE SERVICES ARE AVAILABLE **AT MY FACILITY** AND I AM SUFFICIENTLY FAMILIAR WITH THEM TO RESPOND TO THESE QUESTIONS WITH REASONABLE ACCURACY ☐
(PLEASE COMPLETE ALL QUESTIONS IN THIS SECTION)

2.1 WHICH OF THE FOLLOWING EARLY DETECTION PROCESSES OCCUR AT YOUR FACILITY?	**YES**	**NO**	**DON'T KNOW**
A. Breast education	( )	( )	( )
B. Do health care providers perform CBE on women as part of general care for early detection purposes?	( )	( )	( )
C. Does your facility encourage or teach BSE?	( )	( )	( )
D. Does your facility perform mammography of women without breast symptoms as part of a **population-based** mammographic screening program?	( )	( )	( )
E. Does your facility offer **opportunistic** mammographic screening of women without breast symptoms (i.e. mammography is offered to women when they attend the facility for unrelated reasons)?	( )	( )	( )
F. Does your facility offer mammographic screening of women without breast symptoms at a screening clinic (i.e., women can attend for breast screening, but it is not part of a systematic screening program)?	( )	( )	( )
G. Is mammographic screening free to women if their health insurance doesn't cover it?	( )	( )	( )
H. Do you evaluate women who come to your center with palpable breast lumps using **ultrasound**?			
2.1.1 Can you refer patients to another health facility in the event of a breast cancer suspicion?	( )	( )	( )

*Complete table below if you answered **NO** to any of the above*

2.2 WHY ARE THE SERVICES NOT OFFERED AT THIS FACILITY?

A. Breast education	
B. CBE	
C. Encouraging BSE	
D. Population based mammographic screening	
E. Opportunistic mammographic screening	
F. Screening clinic	
G. Breast ultrasound	

3. PATIENT DATA, RECORDS AND TRACKING

3.1. APPROXIMATELY HOW MANY STAFF WORK IN THE FOLLOWING DEPARTMENT?	NUMBER	THE FACILITY DOESN'T HAVE THIS DEPARTMENT	DON'T KNOW
A. Medical records		( )	( )

3.2. PLEASE ANSWER THE FOLLOWING REGARDING THE STATUS AND MAINTENANCE OF MEDICAL RECORDS	YES	NO	DON'T KNOW
A. Are paper-based patient medical records maintained by your facility?	( )	( )	( )
B. Are electronic patient medical records maintained by your facility?	( )	( )	( )
C. Are medical records held/maintained by patients?	( )	( )	( )
D. Is it the responsibility of the patient to bring their records to medical appointments?	( )	( )	( )
E. Does your facility have a system for following patients suspected of having breast cancer?	( )	( )	( )
F. Does your facility maintain contact with patients by telephone, mail or other methods? (Specify other methods if applicable)	( )	( )	( )
G. Does your facility send information about patients to other providers outside of your facility – for example if patients are referred to another hospital for diagnostic examination or treatment?	( )	( )	( )
H. Does your facility utilize a unified medical record number for each patient that is used throughout the facility?	( )	( )	( )
I. Is there a unified medical record/patient ID number used across different heath facilities in your country?	( )	( )	( )

3.3. PLEASE INDICATE IF YOUR FACILITY RECORDS INFORMATION ABOUT BREAST CANCER INCIDENCE AND OUTCOME	YES	NO	DON'T KNOW

A. Is there a hospital-based cancer registry in your facility?	( )	( )	( )
*If **NO** please go to section 4, if **YES** continue below*			
B. Does it contribute data to a population –based regional cancer registry?	( )	( )	( )
C. Does it contribute data to a population-based national cancer registry?	( )	( )	( )
Which of the following data do you collect?			
D. **Personal identification** *(Name, age, sex, registration number, contact information, ethnicity)*	( )	( )	( )
E. **Tumor data** *(Incidence date; Topography (site); Morphology (histology); Behavior; Method of first detection; Extent of disease)*	( )	( )	( )
F. **Diagnosis** *(Basis of diagnosis; Diagnostic examination; Certainty of diagnosis)*	( )	( )	( )
G. **Referral** *(Date of referral; referral facility)*	( )	( )	( )
H. **Follow-up** *(Date of last contact; Status at last contact (alive, dead, emigrated, unknown); Date of death; Cause of death; Place of death)*	( )	( )	( )

4. Funding

4.1. HOW DO THE MAJORITY OF PATIENTS PAY FOR GENERAL & BREAST HEALTH SERVICES AT YOUR FACILITY? *(If you select more than one answer, please rank your answers in the order of importance with 1 being the most important, 2 being the second most important, etc.)*	**GENERAL HEALTH SERVICES**	**BREAST HEALTH SERVICES**
A. Government funding (free for all patients)	( )	( )
B. Private Insurance (purchased by patients or their employers)	( )	( )
C. Patient/Family pays 100% of the cost (out of pocket expense)	( )	( )
D. Patient/Family pays part of the cost	( )	( )

5. HEALTH PROMOTION ACTIVITIES

5.1. WHICH PLATFORM DOES YOUR FACILITY USE TO DISSEMINATE INFORMATION ON BREAST CARE?	**YES**	**NO**	**DON'T KNOW**
A. Leaflets	( )	( )	( )
B. Posters	( )	( )	( )

C. Television	( )	( )	( )
D. Radio	( )	( )	( )
E. Newspaper	( )	( )	( )
F. Social media (facebook, twitter)	( )	( )	( )
G. Other (specify):	( )	( )	( )

5.2. DOES YOUR FACILITY EITHER ALONE, OR IN PARTNERSHIP WITH OTHER ORGANIZATIONS, PROVIDE ANY INFORMATION TO WOMEN ON BREAST CARE? *If your facility utilizes national or regional resources for this purpose, please select '**YES**'.*	**YES**	**NO**	**DON'T KNOW**
A. Awareness of breast cancer risk factors	( )	( )	( )
B. Signs and symptoms of breast cancer	( )	( )	( )
C. Information about how to practice breast self-examination	( )	( )	( )
D. The importance of breast cancer early detection	( )	( )	( )
E. Outreach/education encouraging CBE for age groups at high risk	( )	( )	( )
F. Diagnosing breast cancer	( )	( )	( )
G. Treatment of Breast Cancer	( )	( )	( )
H. Importance of screening mammography	( )	( )	( )
I. Information about where to access breast healthcare	( )	( )	( )
J. Information about where to access breast cancer support networks	( )	( )	( )
K. Information about access to financial resources for breast cancer (to pay for diagnosis or treatment, for example)	( )	( )	( )

5.3. DOES YOUR FACILITY PROVIDE PSYCHOSOCIAL SUPPORT FOR BREAST CARE?	**YES**	**NO**	**DON'T KNOW**
A. Patient and family education/support groups	( )	( )	( )
B. Peer support by trained volunteers	( )	( )	( )

C. Spiritual support: community- or religious-based	( )	( )	( )
D. Psychosocial support by health professionals	( )	( )	( )

6. REFERRAL PATHWAY

6.1. IS YOUR FACILITY ABLE TO REFER TO ANY SPECIALITY BREAST CANCER REFERRAL CENTRE?	**YES**	**NO**	**DON'T KNOW**
	( )	( )	( )
*If **YES**, please list below*			
A.			
B.			
C.			
D.			
E.			

6.2. ESTIMATED DISTANCE BETWEEN YOUR FACILITY AND REFERRAL FACILITY	**KILOMETERS**	**HOURS**
A.		
B.		
C.		
D.		
E.		

6.3. MEANS OF TRANSPORTATION AVAILABLE FOR REFERRED PATIENTS	**YES**	**NO**	**DON'T KNOW**

A. Ambulance	( )	( )	( )
B. Public transport	( )	( )	( )
C. Private vehicle	( )	( )	( )
D. Other (Specify):	( )	( )	( )

7. HUMAN RESOURCES

7.1. HOW MANY STAFF WORK IN THE FACILITY/ HOW MANY STAFF ARE ATTACHED TO THIS FACILTY IN THE CASE OF COMMUNITY HEALTH WORKERS?	NONE	NUMBER	DON'T KNOW
A. Clinical officers	( )		( )
B. Nurses	( )		( )
C. Allied health workers	( )		( )
D. Pharmacists	( )		( )
E. Community health workers	( )		( )
F. Other (specify):	( )		( )

7.2. WHICH OF THE STAFF PROVIDE BREAST CANCER DETECTION SERVICES?	TRAIN WOMEN ON BSE	CBE	MAMMOGRAPHY	BREAST ULTRASOUND
A. Clinical officers				
B. Nurses				
C. Allied health workers				
D. Pharmacists				
E. Community health workers				
F. Other (specify):				

7.3. WHICH OF THE STAFF HAVE RECEIVED TRAINING ON EARLY DETECTION OF BREAST CANCER?	SELECT
A. Clinical officers	( )

B. Nurses	( )
C. Allied health workers	( )
D. Pharmacists	( )
E. Community health workers	( )
F. Other (specify):	( )

7.4. WHICH OF THE STAFF HAVE RECEIVED TRAINING ON EARLY DETECTION OF ANY OTHER CANCER?	SELECT	WHICH CANCER?
A. Clinical officers	( )	
B. Nurses	( )	
C. Allied health workers	( )	
D. Pharmacists	( )	
E. Community health workers	( )	
F. Other (specify):	( )	

8. OTHER HEALTH SERVICES

8.1. WHICH SERVICES ARE DELIVERED AT YOUR FACILITY?	YES	NO	DON'T KNOW
A. Malaria	( )	( )	( )
B. HIV/AIDs	( )	( )	( )
C. Tuberculosis	( )	( )	( )
D. Pneumonia	( )	( )	( )
E. Diarrhoea	( )	( )	( )
F. Maternal and child health	( )	( )	( )
G. Family planning services	( )	( )	( )
H. Sexual health	( )	( )	( )
I. Non-communicable diseases (specify):	( )	( )	( )
J. Basic diagnostic services	( )	( )	( )
K. Other (specify):	( )	( )	( )

9. STRENGTHS & WEAKNESSES

9.1. Identify key challenges facing your health facility with regards to early detection of breast

9.2. Identify key interventions that could be put in place to strengthen your capacity for delivering early detection services.

9.4. If you have any additional comments, please write them below.

Thank you for completing this questionnaire.

Appendix 3.2: Community Health Workers Assessment Questionnaire

Olukalala lw'ebibuuzo by'abasawo b'okubyalo
Ebikolwa eby'okuzuula amangu kookolo w'amabeere

ENDAGA YO OLUKALALA LW'EBIBUUZO: _____

EKYALO_____

OMULUKA _____

OKIKULA: MUKYALA ( ) MWAMI ( )

ENAKU Z'OMWEZI: _ _/ _ _/ _ _ _ _ (olunaku/omwezi/omwaka)

A. ENYANJULA

1.1. Nyonyola mu bumpimpi ku mulimu gwo nga omusawo w'okukyalo

1.2 Byabulamuuki ku bino wamanga by'otuusa ku bantu	Yee	Nedda
A. Omusujja gw'ensiri	( )	( )
B. Akawuka akaleeta mukenenya	( )	( )
C. Akafuba	( )	( )
D. Lubyamira	( )	( )
E. Ekiddukano	( )	( )
F. Eby'obulamu bya maama n'omwana	( )	( )
G. Enkola ya kizaala gumba	( )	( )
H. Eby'obulamu ebyekusa ku kuzaala	( )	( )
I. Kookolo (kookolo ki):	( )	( )
J. Endwadde omuntu zatafuna okuva ku muntu omulala (ndwadde ki?):	( )	( )
K. Ebilala (Bimenye):	( )	( )

1.3 Eby'obulamu by'abakazi	Yee	Nedda
A. Olina eby'obulamu by'otuusa ku bantu nga bikwaata ku bakyala bokka?	( )	( )
Bwoba olina, byogere.		
B. Wenyigira mu mirimu egikwaata ku kulabirira amabeere?	( )	( )
C. Abasawo b'okubyaalo abasajja bakola emirimu egikwaata ku kulabirira amabeere mubakazi?		
D. Bakazi nga bameka b'okolako buli mweezi?	**Omuwendo**	**Simanyi**
	( )	( )

1.4 Mbuulira oba wali ofunyeyo omusomo gwona nga omusawo w'okukyalo kubino wamanga?	Yee	Nedda
A. Omusomo okukubangula mu mulimu gwo nga omusawo w'okukyalo?		
B. Omusomo ogukwatagana ku kuzuula kookolo w'amabeere?		
C. Omusomo ogukwatagana ku kulabirira amabeere?		
D. Omusomo ku ndwadde omuntu zatafuna okuva ku muntu omulala?		
Bwoba wafuna omusomo ku bwetwogeddeko wagulu, nyonyola ebikwata ku musomo ogwo.		

2 Akasiimo				
2.1. Kasiimo ki kofuna olw'okukola omulimu guno?		**Akuwa akasiimo**		
		Gavumenti	**Pulojekiti**	**Ekitongole ky'obwanakyeewa**
A. Sifuna kasiimo	( )			
B. Akasiimo ka sente	( )			

C. Akasiimo akatali ka sente (kasiimo ki?)	( )			
		( )	( )	( )
		( )	( )	( )
		( )	( )	( )
		( )	( )	( )
		( )	( )	( )

3. Okuzuula kookolo w'amabeere		
3.1 Ebibuuzo ebisooka	**Yee**	**Nedda**
A. Wali owuliddeko ku kookolo W'amabeere?	( )	( )
B. Omanyi engeri kookolo w'amabeere gyasobola okuzuulibwamu?	( )	( )
Bwoba omanyi, nkola ki ey'okumuzuula amangu gyomanyi?		
C. Omuntu okwekebera amabeere	( )	( )
D. Okukebera amabeera mu dwaliro	( )	( )
E. Okukebera amabeera nga bakozesa enkola gyebayita "Mammography" oba ekyuuma mu ddwaliro	( )	( )
F. Okukebera amabeere nga bakozesa enkola ya scani	( )	( )
G. Ekilala (kyogere)	( )	( )

1.2 Nga omusawo w'okukyaalo, mirimu ki gy'owereza ku gino wamanga?	**Yee**	**Nedda**	**Simanyj**
A. Okumanyisa abantu ku bintu ebiyinza okubaviirako okufuna kookolo w'amabeere	( )	( )	( )
B. Obubonero obwekusa ku kookolo w'amabeere	( )	( )	( )
C. Obubaka obukwata ku ngeri gy'oyinza okukebera amabeere go	( )	( )	( )
D. Emigaso egyiri mu kuzuula kookolo w'amabeere amangu	( )	( )	( )

E. Enkungaana oba emisomo mukitundu kyo egikubiriza abantu abali mumyaka egyisinga okulwala kookolo w'amabeere okukukebera amabeere gaabwe mu ddwaliro	( )	( )	( )
F. Emigaso gyokwekebeza kookolo wabameere nga okozesa enkola eya mammography	( )	( )	( )
G. Obubaka obwekusa kugyosobola okufuna obujjanjabi bw'amabeere	( )	( )	( )
H. Obubaka obwekusa ku bibinja oba ebibiina ebilwanyisa kookolo wambeere	( )	( )	( )
I. Obubaka obwekuusa ku ngeri gy'oyinza okukwatagana n'ebibiina ebigaba obuyambi eri abalwadde ba kookolo w'amabeere	( )	( )	( )
J. Obubaka obwekusa ku ngeri gy'oyinza okuyambibwa n'essente ez'okuzuula oba okujjanjaba kookolo w'amabeere	( )	( )	( )

4. Okutumbula eby'obulamu

4.1 Otuusa otya obubaka obwekusa ku by'obulamu eri abakazi mu kitundu kyo?	**Yee**	**Nedda**	**Simanyi**
A. Nga okyalidde amaka	( )	( )	( )
B. Mu nkungaana z'okukyalo	( )	( )	( )
C. Abantu b'omukitundu nga bannebuuzizaako	( )	( )	( )
D. Nga nkozesa obupapula obuliiko obubaka obukwaata ku by'obulamu	( )	( )	( )
E. Ebipandde	( )	( )	( )
F. Telefayina	( )	( )	( )
G. Radiyo	( )	( )	( )

H. Amawulire g'empapula	( )	( )	( )
I. Emikutu gya yintaneeti (facebook, twitter)	( )	( )	( )
J. Ebilala (byogere):	( )	( )	( )

5. Ebiyamba n'ebiziyiza

5.1. Mu ndowozayo, buzibuki by'osanga obwekuusa kubusobozibwo mu kuyamba okuzuula amangu kookolo w'amabeere?

5.2. Mu ndowozayo, bintu ki ebisobola okutekebwa mu nkola okunyweza obusobozi bwo mu kuyambako okuzuula amangu kookolo w'amabeere?

1.3. Bitongole ki ebilala ebisobola okuyamba abasawo b'okubyalo ku mulimo gw'okuzuula amangu kookolo w'amabeere?

5.4. Bwoba olina ensonga endala yonna, gyimbuulire.

Webale kuddamu ebibuuzo ebyo

Appendix 3.3: Data Entry Sheet for CHWs Assessment

Screenshots of data entry sheet:

DEMOGRAPHICS					SECTION 1: OVERVIEW																	
					1.2											1.3				1.4			
IDENTIFIER	VILLAGE	PARISH	SEX	DATE OF SURVEY	A	B	C	D	E	F	G	H	I	J	K	A	B	C	D	A	B	C	D

Strengths & Weaknesses			
5.1	5.2	5.3	5.4
Key Challenges	Interventions	Organizations that can support with early detection of BC	Additional comments

General Notes:

1. Unless otherwise stated, YES = 1, NO = 2, DON'T KNOW = 0
2. Enter responses on specify in Qualitative sheet
3. BC = Breast Cancer

Appendix 3.4: Semi-structured Interview Guides

Semi-Structured Interview Guides - CHWs

Section 1: Practicable solutions to promote early detection of breast cancer at PHC level

My previous research indicated that women in Kajjansi town council do not detect breast cancer early because of the following challenges:

- Low knowledge and awareness
- Negative attitude
- Negative beliefs
- Health practices
- Social stigma
- Mass media challenges
- Poverty
- Distance to PHC facilities
- Sex of the health worker

1. In your opinion, what are the solutions to the identified challenges?
2. Are there other challenges associated with early detection of breast cancer that you would like to discuss? What are the solutions to these challenges? [In your opinion, what is the underlying challenge in relation to early detection of breast cancer in Kajjansi town council? How can this challenge be addressed?]
3. How can the primary health care capacity be strengthened to deliver breast cancer detection services?

Section 2: Resources to support early detection of breast cancer

1. In your opinion, what resources are required to support with early detection of breast cancer?
2. How can CHWs support with delivery of early detection services for breast cancer?
3. What services do women visit the health centre for regularly? [e.g maternal healthcare services]
4. In your opinion, what additional resources are required to promote early detection of breast cancer for women?

Section 3: Engagement of women in health service delivery

1. How do VHTs engage women in health issues?
2. How can women be engaged to promote early detection of breast cancer?

Semi-Structured Interview Guide- NGOs

Section 1: Introduction: Overview of the organisation

- What is the purpose of your organisation? [When was it founded? Why was it founded]
- How is your organisation funded?
- Can you tell me about your health projects/programmes? [Do you do any programmes in relation to breast cancer detection/control/cancer/NCDs]
- How do you decide on or select the programmes to implement? [What drives your health projects/programmes]
- How do you carry out your health projects/programmes? [Through health centres or do you go directly to the communities?]
- Who do you work with and how do you work with them [CHWs, health centres, government officials, etc.]?
- How do you engage with women in the delivery of your health projects/ programmes?
- What links do you have with other organisations in Uganda or elsewhere? How do you work with these organisations?
- What challenges do you face with your health programmes/projects? How do you address these challenges? [issues around sustainability]

Section 2: Practicable solutions to promote early detection of breast cancer

My previous research indicated that women in Kajjansi town council do not detect breast cancer early because of the following challenges:

- Low knowledge and awareness
- Negative attitude
- Negative beliefs
- Health practices
- Social stigma
- Mass media challenges
- Lack of capacity building for CHWs
- Weak PHC capacity
- Poverty
- Distance to PHC facilities
- Gender norms [Have you encountered any issues regarding sex of health workers? How did you address it?]

1. In your opinion, what are the solutions to the identified challenges?
2. Are there other challenges associated with early detection of breast cancer that you would like to discuss? What are the solutions to these challenges? [In your opinion, what is the underlying challenge in relation to early detection of breast cancer in Uganda? How can this challenge be addressed?]
3. From your perspective, how can the primary health care capacity be strengthened to deliver breast cancer detection services?

4. In your opinion, how can NGOs contribute to breast cancer detection/NCDs detection for women living in semi-rural communities?

Section 3: Resources to support early detection of breast cancer

1. In your opinion, what resources are required to support with early detection of breast cancer?
2. How can CHWs support with delivery of early detection services for breast cancer?
3. How can existing primary healthcare services support early detection of breast cancer for women? [e.g maternal healthcare services]

Section 4: Engagement of women in health service delivery

1. How can women be engaged to promote early detection of breast cancer?

Additional question/comment

Are there other NGOs working on breast cancer that you can recommend?

Semi-Structured Interview Guide- District Health Team

Introduction

- Please tell me about the Wakiso District Health Team
- What is your role? Explain
- What does the District Health Team do in relation to breast cancer detection? Or NCDs generally.

Section 1: Practicable solutions to promote early detection of breast cancer at PHC level

My previous research indicated that women in Kajjansi town council do not detect breast cancer early because of the following challenges:

- Weak primary health care capacity
- Lack of capacity building for CHWs
- Weak community outreach
- Insufficient government funding
- Distance to PHC facilities
- Gender norms
- Poverty

1. In your opinion, what are the solutions to the identified challenges?
2. Are there other challenges associated with early detection of breast cancer that you would like to discuss? What are the solutions to these challenges? [In your opinion, what is the underlying challenge in relation to early detection of breast cancer in Kajjansi town council? How can this challenge be addressed?]
3. In your opinion, what is the role of the district health team in promoting breast cancer detection?

Section 2: Resources to support early detection of breast cancer

1. In your opinion, what resources are required to support with early detection of breast cancer?
2. How can CHWs support with delivery of early detection services for breast cancer?
3. How can existing primary healthcare services support early detection of breast cancer for women? [e.g maternal healthcare services]

Section 3: Engagement of women in health service delivery

1. How do you engage with women in the district?
2. How can women be engaged to promote early detection of breast cancer?
3. How are health services delivered to meet the needs of women?

Semi-Structured Interview Guide- Primary health care centres

Section 1: Practicable solutions to promote early detection of breast cancer

My previous research indicated that women in Kajjansi town council do not detect breast cancer early because of the following challenges:

- Low knowledge and awareness
- Negative attitude
- Negative beliefs
- Health practices
- Social stigma
- Weak social support network
- Weak community outreach
- Mass media challenges
- Poverty
- Gender norms

1. In your opinion, what are the solutions to the identified challenges?
2. Are there other challenges associated with early detection of breast cancer that you would like to discuss? What are the solutions to these challenges? [In your opinion, what is the underlying challenge in relation to early detection of breast cancer in Kajjansi town council? How can this challenge be addressed?]
3. How can your health centre capacity be strengthened to deliver breast cancer detection services? How can your health centre contribute to the early detection of breast cancer?

Section 2: Resources to support early detection of breast cancer

1. How can CHWs support with delivery of early detection services for breast cancer?
2. How can existing primary healthcare services support early detection of breast cancer for women? [e.g maternal healthcare services]
3. In your opinion, what resources are required to promote early detection of breast cancer for women?

Section 3: Engagement of women in health service delivery

1. How do you engage with women on issues relating to their health needs?
2. How can women be engaged to promote early detection of breast cancer?
3. How are health services delivered to meet the needs of women?

Semi-Structured Interview Guide- Ministry of Health

Section 1: Introduction

- Can you tell me about your department? When and why was it founded?
- What does your department do in terms of policy development? How are the needs of women considered in your health policies?
- How are the polices implemented at community level?
- Can you tell me about your health projects/programmes? How are they funded? How are they implemented?
- How do you decide on or select the programmes to focus on? [What drives your health projects/programmes]
- Who do you work with and what are their roles? [CHWs, health centres, other MoH departments etc]
- What challenges do you face with your health programmes/projects? How do you address these challenges? [e.g. funding]

Section 2: Practicable solutions to promote early detection of breast cancer at PHC level

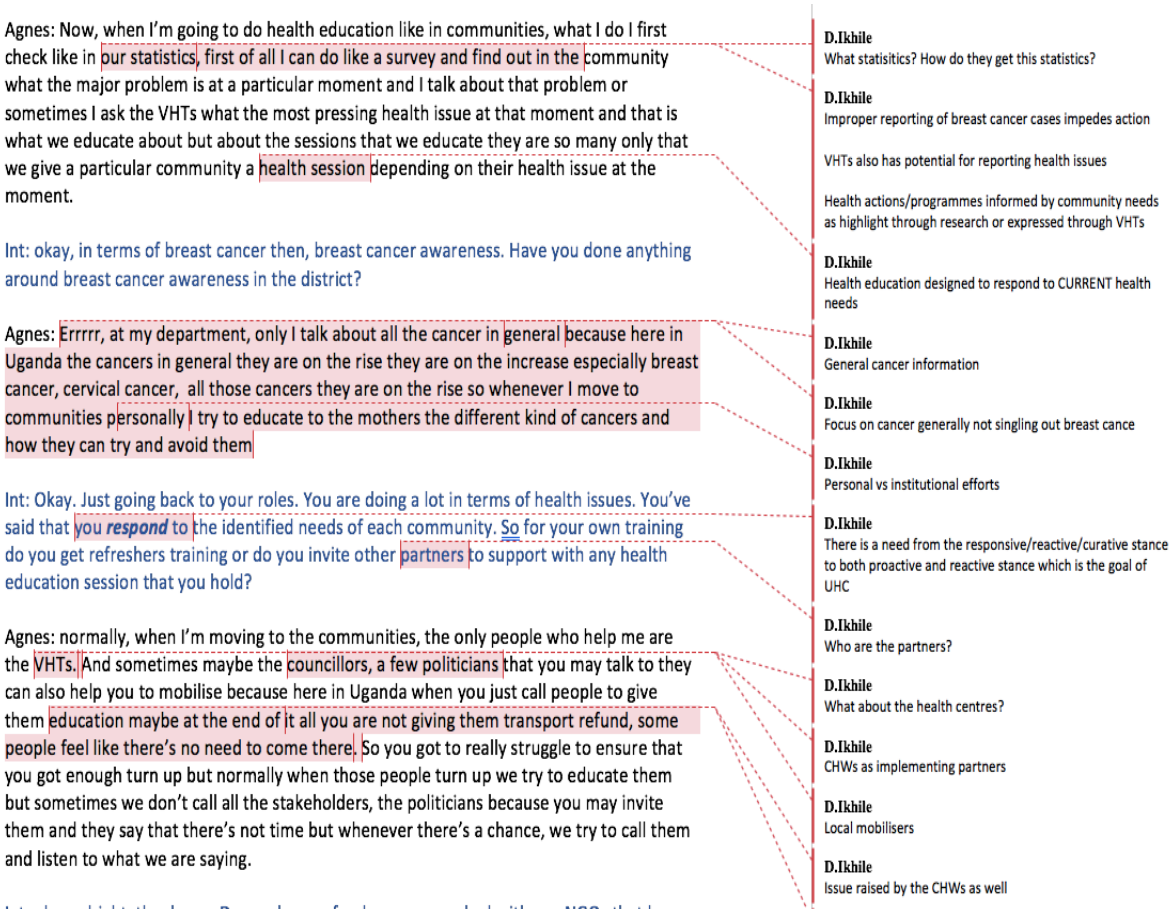
- Does your department carry out any programme(s) relating to breast cancer or other NCDs? How?
- How can the national breast cancer policies/programmes (if any) be translated at community level?
- My previous research indicated that breast cancer detection services are not provided at PHC level in Kajjansi because of the following challenges:
  - Lack of guiding national cancer policy
  - Lack of training for health workers
  - Lack of training for CHWs
  - Insufficient government funding
  - Reliance on foreign aid
  - Distance to PHC facilities
  - Gender norms
  - Poverty

1. In your opinion, what are the solutions to the identified challenges?
2. What other challenges does the MoH face in relation to breast cancer detection/management? How can these be solved?

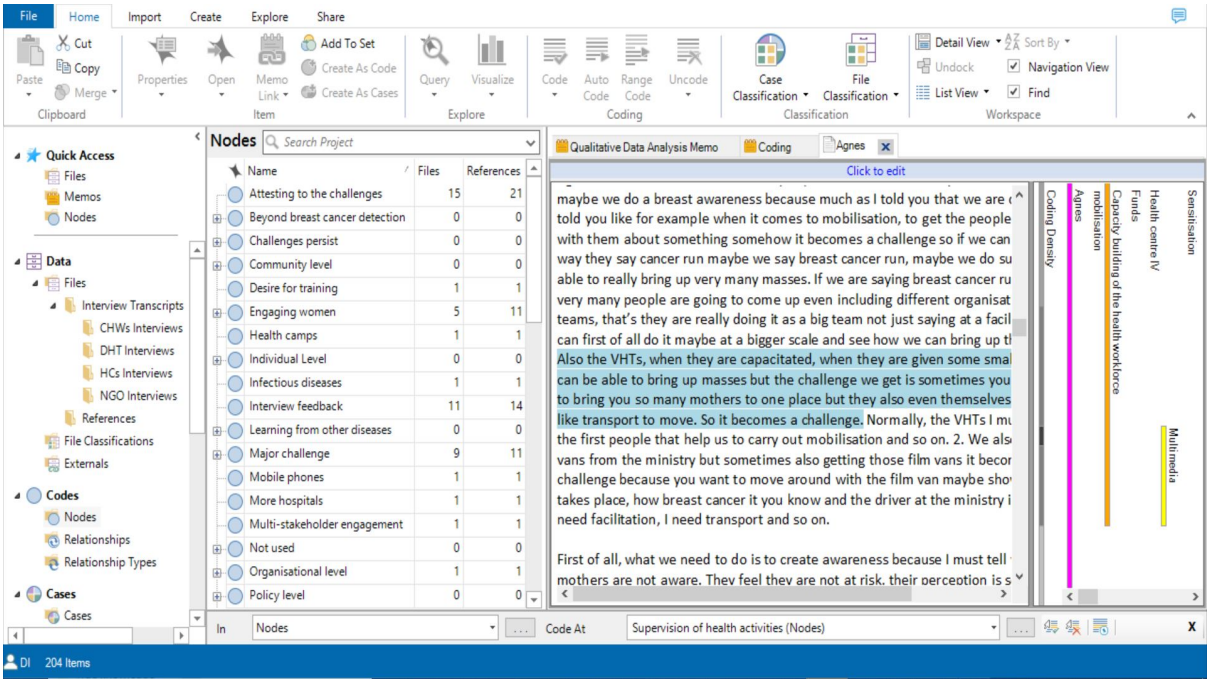
Section 3: How to strengthen the PHC capacity for breast cancer detection

1. How can the primary health care capacity be strengthened to deliver breast cancer detection services?
2. What would be feasible for breast cancer detection at the primary health care level? How can the government support with this?
3. How can the government support CHWs to provide breast cancer detection services?
4. What existing resources can be used to promote breast cancer detection? And how? What other resources are required?

Appendix 3.5: First Cycle Coding on Microsoft Word



Appendix 3.6: Second Cycle Coding on NVivo



Appendix 3.7: Participants Information for the Quantitative Data Collection

PARTICIPANT INFORMATION SHEET

Exploring how a multilevel approach can strengthen primary health care for promoting early detection of breast cancer in Ugandan women

Thank you for considering to participate in this study. Before we begin, it is important you understand why the research is being conducted, and your role as a participant. Please take your time to read the information below carefully and consult your colleagues or family/friends if you so wish.

This survey should take approximately 30 minutes to complete.

What is the purpose of the study?
The purpose of this study is to explore how a multilevel approach can strengthen primary health care for promoting early detection of breast cancer in women living in Ssisa sub-county, Uganda. This study will be conducted in two phases. The purpose of this first phase is to conduct a situation analysis of early detection services for breast cancer at primary health care facilities.

Who is running this study?
The project is being conducted by Deborah Ilaboya, a PhD student from the School of Social Sciences at Nottingham Trent University. Access to this research is being granted through partnership between the School of Social Sciences, Nottingham Trent University, UK and School of Public Health, Makerere University, Uganda.

Who is funding this study?
The study is funded by Nottingham Trent University, UK.

Why have I been chosen to take part?
You have been selected to participate because of your expertise and experience as a stakeholder in health service delivery which would provide invaluable insights to this research.

Do I have to take part?
No, your participation is entirely voluntary. You are under no obligation to complete the survey.
If you do decide to take part, you will be given this information sheet to keep, and you will also be asked to sign a consent form. You are free to withdraw at any time during the survey or **2 WEEKS FROM TODAY.**

If you decide not to take part, or to withdraw at any stage, you will not be asked to give us any reasons and your withdrawal will not get back to your supervisor/manager.

What do you want me to do?
We would like you to complete a questionnaire lasting approximately 30 minutes, either at your workplace or a selected location convenient for you. The questionnaires will be administered by Deborah Ilaboya with the assistance of Carol Namata (School of Public Health, Makerere University) who is providing research support.

What will happen to the information I give in my interview?
Your response will be entered into a database and analysed by Deborah Ilaboya. The analyses will inform the second phase of this study which will be conducted at a later stage and feed into the results of this study. This analyses may also be used as part of a publication.

At the end of the study, all data collected will be retained on an external drive. However, the questionnaires will be fully anonymised before they are archived. Any information that identifies you or your organisation, or that gives any clues to your identity, will be removed. This is to ensure that no data can be traced back to you.

How will the research team protect my confidentiality and anonymity.
The data collected will be handled only by members of the research team. Hard copies of questionnaires would be securely locked in a filing cabinet. Electronic files will be kept on password protected computer in encrypted files in line with the Nottingham Trent University's code of ethics only accessible to the research team. Back up files will be stored on the researcher's personal Nottingham Trent University Onedrive cloud storage.

You will not be named or otherwise identified in any publication arising from this research. The researcher will exercise all possible care to ensure that you or the organisation you work for cannot be identified in the write-up of findings or any publications.

What are the possible disadvantages and risks in taking part?
The main cost to you will be the time taken to complete the questionnaire. The main risk is that you might give us information about yourself or your organisation that has never been published. However, as outlined above, any information you do provide will be kept anonymous and secure. In addition, you can choose not to answer any of the questions or withdraw your data at any time until the final date specified for withdrawal of data (2 weeks from today).

The researcher will not seek information about identifiable patients, clients or colleagues, or access to files about patients or clients.

What are the possible benefits?
We hope that you will find the research process interesting, and will take satisfaction from helping to develop a greater understanding of barriers to early breast cancer detection. We also hope that you will find the results interesting and helpful to your work/life/community.

What will happen to the results?
We will write up the results which will feed into the PhD thesis and also form part of peer-reviewed articles. The results will also be presented at conferences and seminars.

At the end of the study, we will also publish a short, executive summary of our results and recommendations. and will circulate it widely amongst policy makers and local managers.

Has anyone reviewed the study?
The project has received ethical clearance from Nottingham Trent University, College of Business, Law and Social Sciences Research Ethics Committee.

Who is responsible if anything goes wrong?
The researcher, Deborah Ilaboya is responsible for the conduct of this study. Please feel free to contact the research team (contact details provided below) if you have any concerns about this study.

How can I find out more about this project and its results?
For more information about the study, please contact a member of the research team on the following email address or phone numbers:

Deborah Ilaboya
xxxxxxxxx
Tel: xxxxxxxxx (UK)

Dr Linda Gibson
xxxxxxxxx
Tel: xxxxxxxxx (UK)

David Musoke
xxxxxxxxx
Tel: xxxxxxxxx (Uganda)

INFORMED CONSENT

Exploring how a multilevel approach can strengthen primary health care for promoting early detection of breast cancer in Ugandan women

Please read and confirm your consent to participate in this project by initialling the appropriate box(es) and signing and dating this form

1. I confirm that the purpose of the project has been explained to me, that I have been given information about it in writing, and that I have had the opportunity to ask questions about the research ☐

2. I understand that my participation is voluntary, and that I am free to withdraw at any time during the survey without giving any reason ☐

3 I understand that I am not able to withdraw my responses after two weeks from the survey date ☐

4. I agree to take part in this survey ☐

Name of respondent: Signature:

Date:

Name of researcher taking consent: Signature:

Date:

Appendix 3.8: Participants Information for the Qualitative Data Collection

PARTICIPANT INFORMATION SHEET- SKYPE INTERVIEWS

Exploring how a multilevel approach can strengthen primary health care for promoting early detection of breast cancer in Ugandan women

Thank you for agreeing to participate in this study. Before we begin, it is important you understand why the
Thank you for agreeing to participate in this study. Before we begin, it is important you understand why the research is being conducted, and your role as a participant.

Please take your time to read the information below carefully and consult your colleagues or family/friends if you so wish. Please feel free to ask me anything that is unclear before we begin.

What is the purpose of the study?
The purpose of this study is to provide evidence on how primary health care (PHC) capacity can be strengthened to promote early detection of breast cancer in women in Kajjansi town council, Uganda. This study is being conducted in two phases. This exercise is a follow-up on the first phase (conducted in February 2017), and its purpose is to gather evidence on how challenges around early detection of breast cancer at primary health care level can be addressed. I am conducting semi-structured interviews with key informants from different organisations and community health workers. I will also be conducting focus group discussions with women in the community.

Who is running this study?
The project is being conducted by Deborah Ikhile, a PhD student from the School of Social Sciences at Nottingham Trent University. It is a follow-up on my Masters research conducted in 2015 and data collection exercise conducted in February 2017.

Who is funding this study?
The study is funded by Nottingham Trent University, UK.

Why have I been chosen to take part?
You have been selected to participate because of your experience and expertise as a stakeholder in primary health care delivery which would provide invaluable insights to this research.

Do I have to take part?
No, your participation is entirely voluntary. You are under no obligation to complete the participate in this research. If you do decide to take part, you will be given this information sheet to keep, and you will also be asked to sign a consent form. You are free to withdraw at any time during the data collection or **2 WEEKS FROM TODAY.** To withdraw after the data collection, kindly contact Deborah Ikhile or any other member of the research team through the contact details provided below.

If you decide not to take part, or to withdraw at any stage, you will not be asked to give us any reasons and your withdrawal will not get back to your supervisor/manager.

What do you want me to do?
I would like you to take part in a skype interview lasting between 30 to 60 minutes at your convenience. The interview will be conducted by Deborah Ikhile.

What will happen to the information I give in my interview?
Your response will be recorded with an audio device, transcribed (a written document of what was said) and analysed by Deborah Ikhile. The analyses will inform the results of this study and be included in my thesis. The analyses may also be used as part of a publication.

At the end of the study, all data collected will be retained on a password protected external drive. Any information that identifies you or your organisation, or that gives any clues to your identity, will be removed from the interview transcripts. This is to ensure that no data can be traced back to you.

How will the research team protect my confidentiality and anonymity.
The data collected will be handled only by myself and members of the research team. No sensitive information about yourself or your organisation will be collected as part of the data collection. The interview transcripts will be kept on password protected computer in encrypted files in line with the Nottingham Trent University's code of ethics only accessible to the research team. Back up files will be stored on the researcher's personal Nottingham Trent University Onedrive cloud storage.

You will not be named or otherwise identified in any publication arising from this research. The researcher will exercise all possible care to ensure that you or the organisation you work for cannot be identified in the write-up of findings or any publications.

What are the possible disadvantages and risks in taking part?
The main cost to you will be the time taken to participate in the interview. The main risk is that you might give us information about yourself or your organisation that has never been published. However, as outlined above, any information you do provide will be kept anonymous and secure. In addition, you can choose not to answer any of the questions or withdraw your data at any time until the final date specified for withdrawal of data (**2 weeks from today**).

What are the possible benefits?
I hope that you will find the research process interesting, and will take satisfaction from helping to develop a practicable solutions in order to promote early breast cancer detection. I also hope that you will find the results interesting and helpful to your work/life/community.

What will happen to the results?
I will write up the results which will feed into the PhD thesis an also form part of peer-reviewed articles. The results will also be presented at conferences and seminars and published in journals.

Has anyone reviewed the study?
The project has received ethical clearance from Nottingham Trent University, College of Business, Law and Social Sciences Research Ethics Committee.

Who is responsible if anything goes wrong?
The researcher, Deborah Ikhile is responsible for the conduct of this study. Please feel free to contact the research team (contact details provided below) if you have any concerns about this study.

How can I find out more about this project and its results?
For more information about the study, please contact a member of the research team on the following email address or phone numbers:

Deborah Ikhile
xxxxxxxxx
Tel: xxxxxxx
Skype ID: xxxxxxxx

Dr Linda Gibson
xxxxxxxxx
Tel: xxxxxxx

David Musoke
xxxxxxxxx
Tel: xxxxxxx

Dr Sarah Seymour-Smith
xxxxxxxxx
Tel: xxxxxxxx

INFORMED CONSENT

Exploring how a multilevel approach can strengthen primary health care for promoting early detection of breast cancer in Ugandan women

Please read and confirm your consent to participate in this project by initialling the appropriate box(es) and signing and dating this form

1. I confirm that the purpose of the project has been explained to me, that I have been given information about it in writing/talking, and that I have had the opportunity to ask questions about the research ☐

2. I understand that the interview will be conducted via skype ☐

3. I give permission to be tape-recorded by the researcher, on the understanding that the tape will be handled in a secure manner ☐

4. I understand that my participation is voluntary, and that I am free to withdraw at any time during the interview without giving any reason ☐

5. I understand that I am not able to withdraw my responses after two weeks from today ☐

6. I agree to take part in this study ☐

_____	_____	_____
Name of respondent	Date	Signature

_____	_____	_____
Name of researcher	Date	Signature

Appendix 4.1: List of Parishes and Villages in Kajjansi Town Council

		Parish											Total
		BULWANYI	BWEYA	KASUKU	KITENDE	NAKAWUKA	NAMULANDA	NANKONGE	NKUNGULUTALE	NSAGGU	SSISA	WAMALA	
Village	BUDANIERI	0	0	0	0	0	0	0	0	0	5	0	5
	BULONDE	0	3	0	0	0	0	0	0	0	0	0	3
	BULWANYI CENTRAL	5	0	0	0	0	0	0	0	0	0	0	5
	BUMPENJE	6	0	0	0	0	0	0	0	0	0	0	6
	BUSWA	0	0	5	0	0	0	0	0	0	0	0	5
	BUTAKESU	0	0	0	0	0	0	5	0	0	0	0	5
	BUTEGA	0	0	0	0	0	0	0	0	4	0	0	4
	BUZZI	0	0	0	0	0	3	0	0	0	0	2	5
	BWEBAJJA	0	1	0	5	0	0	0	0	0	0	0	6
	BWEYA CENTRAL	0	12	0	0	0	0	0	0	0	0	0	12
	DDEWE	0	5	0	0	0	0	0	0	0	0	0	5
	DYANGO	0	0	0	0	4	0	0	0	0	0	0	4
	GAYAZA	0	0	0	0	0	0	0	0	0	3	0	3
	JJANYI	0	1	0	0	0	0	0	0	0	0	0	1
	K.K.B	0	6	0	0	0	0	0	0	0	0	0	6
	KAAMA II	6	0	0	0	0	0	0	0	0	0	0	6
	KAGA	0	0	0	0	0	0	0	0	0	3	0	3
	KAGULU	0	0	0	0	0	0	0	0	0	4	0	4
	KAJJANSI A	0	0	0	5	0	0	0	0	0	0	0	5
	KAJJANSI B	0	0	0	5	0	0	0	0	0	0	0	5
	KAJJANSI C	0	0	0	5	0	0	0	0	0	0	0	5
	KANYIGO	0	4	0	0	0	0	0	0	0	0	0	4
	KASAALI	0	0	0	0	0	5	0	0	0	0	0	5
	KASUKU	0	0	3	0	0	0	0	0	0	0	0	3
	KATALEMWA	0	0	0	0	5	0	0	0	0	0	0	5
	KATALEMWA BBYA	0	0	0	0	0	0	4	0	0	0	0	4
	KATWE	0	0	0	0	5	0	0	0	0	0	0	5
	KAWOTTO A	0	0	0	4	0	0	0	0	0	0	0	4
	KAWOTTO B	0	0	0	6	0	0	0	0	0	0	0	6
	KISEMBI	0	0	0	0	0	0	0	3	0	0	0	3
	KITENDE A	0	0	0	5	0	0	0	0	0	0	0	5
	KITENDE B	0	0	0	6	0	0	0	0	0	0	0	6
	KITOVU	0	0	0	4	0	0	0	0	0	0	0	4
	LUKOSE	4	0	0	0	0	0	0	0	0	0	0	4
	LUMULI	0	0	0	4	0	0	0	0	0	0	0	4
	LUTABA	0	0	0	0	0	0	0	0	0	0	3	3

	MAKANDWA	0	0	0	5	0	0	0	0	0	0	0	5
	MAWANYI	0	0	0	0	0	7	0	0	0	0	0	7
	MAZZI	0	0	0	0	0	0	0	0	0	2	0	2
	MPUMUDDE	0	0	0	0	7	0	0	0	0	0	0	7
	MUNKABIRA	0	0	0	0	0	0	0	3	0	0	0	3
	NAKAWUKA A	0	0	0	0	5	0	0	0	0	0	0	5
	NAKAWUKA B	0	0	0	0	4	0	0	0	0	0	0	4
	NAKIGALALA A	0	0	0	5	0	0	0	0	0	0	0	5
	NAKIGALALA B	0	0	0	8	0	0	0	0	0	0	0	8
	NAKIGALALA KIFENE	0	0	0	1	0	0	0	0	0	0	0	1
	NALUBUDDE	0	0	0	0	0	0	0	0	4	0	0	4
	NAMBEETA	0	0	0	0	0	0	3	0	0	0	0	3
	NAMULANDA A	0	0	0	0	0	5	0	0	0	0	0	5
	NAMULANDA B	0	0	0	0	0	5	0	0	0	0	0	5
	NAMULANDA C	0	0	0	0	0	5	0	0	0	0	0	5
	NAMUZZI	0	0	0	0	0	0	0	0	0	6	0	6
	NANKONGE CENTRAL	0	0	0	0	0	0	4	0	0	0	0	4
	NGANJO	0	0	0	0	0	4	0	0	0	0	0	4
	NGONGOLO A	0	0	5	0	0	0	0	0	0	0	0	5
	NGONGOLO B	0	0	4	0	0	0	0	0	0	0	0	4
	NKUNGULUTALE CENTRAL	0	0	0	0	0	0	0	5	0	0	0	5
	NSAGGU CENTRAL	0	0	0	0	0	0	0	0	7	0	0	7
	SEKIWUNGA	0	0	0	0	0	8	0	0	0	0	0	8
	SSANDA	0	0	5	0	0	0	0	0	0	0	0	5
	WAMALA CENTRAL	0	0	0	0	0	0	0	0	0	0	5	5
	ZZIRU	0	0	0	0	0	0	0	0	0	0	2	2
Total		21	32	22	68	30	42	16	11	15	23	12	292

Appendix 4.2: Comparison of Human Resources for Primary Health Care in Kajjansi Town Council

Job Title	Nsaggu HC II			Nakawuka HC III			Kajjansi HC IV		
	Approved	**Filled**	**Reported**	**Approved**	**Filled**	**Reported**	**Approved**	**Filled**	**Reported**
Medical Officer (including senior medical officer)	0	0	0	0	0	0	2	0	0
Senior Medical Clinical Officer	0	0	0	1	1	2	0	1	2
Medical clinical officer	0	0	1	1	1		2	1	
Nurses (including: nursing Officer and specialist nurses)	1	1	2	4	3	4	9	8	15
Midwives	1	0	0	2	2	2	3	3	5
Nursing assistant	2	2	2	3	1	0	5	3	3
Health assistant	1	0	0	2	2	2	1	1	4
Health information assistant	0	0	0	0	0	0	1	1	0
Health Inspector (including vector control assistant)	0	0	0	0	0	0	2	2	1
Assistant health educator	0	0	0	0	0	0	1	1	1
Laboratory Technician (including medical laboratory assistant)	0	0	0	2	1	2	2	2	2
Ophthalmic Clinical Officer	0	0	0	0	0	0	1	0	0
Public Health Dental Officer (including dental assistant)	0	0	0	0	0	0	1	1	1
Theatre Assistant	0	0	0	0	0	0	2	1	0
Anaesthetic Assistant	0	0	0	0	0	0	2	1	0
Dispenser	0	0	0	0	0	0	1	1	1
Counsellor	0	0	0	0	0	0	0	0	1
Sub-Total	**5**	**3**	**5**	**15**	**11**	**12**	**35**	**27**	**36**

Appendix 4.3: Breast Cancer Detection Challenges and Prompts used in the Qualitative Data Collection

Level 1 (Socioecological Model)	Level 2 (Broad challenges)	Level 3 (Interview Prompts)
Individual	Low knowledge	• Low knowledge of breast cancer symptoms • Low awareness of breast cancer detection measures
	Negative attitude	• Fear
	Negative beliefs	• Misconceptions about breast cancer • Fatalism
	Health practices	• Poor health seeking behaviour • Reliance on traditional healing system
Community	Stigma	
	Challenges around breast cancer organisations	• Inadequate publicity around early detection of BC • Inadequate breast cancer organisations
Organisational	Weak primary health care capacity	• Limited availability of breast cancer detection services • Inadequate PHC workers • Inadequate breast cancer training for PHC workers • Lack of cancer monitoring system
Structural	Distance to PHC facilities	
	Sex of health workers	
	Poverty	
Policy	Lack of national cancer policy	
	Reliance on foreign aid	
	Inadequate monitoring system for breast cancer	